RECIPE FOR A RAINBOW:
A TRAINING PROGRAMME FOR PARENTS OF CHILDREN WITH CHALLENGING BEHAVIOURS ASSOCIATED WITH AUTISM SPECTRUM DISORDER

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Abstract

Parents of children with Autism Spectrum Disorder (ASD) have to manage a number of challenging behaviours with limited access to resources or knowledgeable professionals. A nine-week parent-training programme developed and tested in this study shows that parents can effectively and independently manage the challenging behaviours associated with ASD. Ten parent-child dyads consisting of a mother and her child with ASD took part in this study. Parents identified three target behaviours in each of the three areas associated with ASD – the 'triad of impairment'- socialisation, communication and restricted interest/cognition.

Positive behaviour change was produced in 29 of the 30 target behaviours over all 'triad' areas. Average adaptive behaviour gains of 13.5 months per child were produced over the nine-week course of instruction. Behaviour gains were maintained and improved over short (7 week) and long-term (7 months) follow-up periods. Parent-participants evidenced generalisation of trained skills over behaviours, individuals and time.

The programme comprised of two components; a) a robust and validated behaviour change approach – Applied Behavioural Analysis and b) a new approach based on Theory of Mind – social understanding. While parent-child dyads were randomly assigned to two groups, each receiving the two components in different order, parents in one group were significantly more stressed. Comparative analyses showed that both components produced effective behaviour change and that neither technique was more significant than the other. However, the social understanding approach appeared to produce larger behaviour change effects in shorter periods of time and was sufficiently powerful to produce child-behaviour change in the group of parents who had major 'stress' and 'poor mood'. Parents reported that the social understanding approach was simple to implement and voiced a preference for this approach over the applied behavioural analysis approach.

During the course of the programme, parent belief in their own ability to control child behaviour increased and stressors associated with child characteristics and the condition of ASD decreased. Parents reported satisfaction with the programme content, length and format and reported that the programme produced socially valid behaviour changes.

A Recipe for Rainbows...

A mother remarked to her six year old son, "Oh
no, look at that big, black cloud. It's going to
rain".
The boy looked up at his mum and replied,
"Oh, mum, it's a recipe for rainbows..."

This story came from one of the parents in the research group. Her son's comment summed up how different the world appears to the child with an Autistic Spectrum Disorder (ASD). We live in a world where objects, actions and events mean particular things and allow us to draw particular conclusions. Children with ASD look at the same objects, actions and events but they draw quite different conclusions because they have a different understanding of what these things mean.

'A recipe for rainbows...' was chosen as the title for this dissertation because it also lends itself to the purpose of this study. The programme developed and presented in this thesis was designed to help parents understand and manage the challenging behaviours associated with their child's condition. In doing so, it aimed to alleviate parent and family stress, improve parent-child relationships and enhance family functioning and harmony. If the programme can be conceptualised as a 'recipe' of techniques and information that allows parents to catch a glimpse of the world through the eyes of the child with ASD, then it is hoped that we may start to see the 'rainbows' – the beauty and peace that signals the end of the storm...

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To you all, much thanks and love. This is dedicated to you all.

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Thesis Overview

This research consists of an experimental study designed to develop and test a parent-training programme for parents of children with Autism Spectrum Disorders (ASD). It seeks to determine whether parents could be trained to independently and effectively manage the challenging behaviours associated with ASD.

Chapter 1 introduces the research project and begins with a review of the literature pertinent to this study including the condition of Autistic Spectrum Disorder, parent stress and parent-training for behaviour management. The condition of Autism Spectrum Disorder (ASD) is introduced by way of historical information and consideration of diagnostic issues, prevalence and proposed causes. The core features of ASD – the 'triad of impairments' are introduced and the three domains – socialisation, communication and restricted imagination/cognition – are briefly outlined. The core features of ASD are proposed to lead to behaviours that are perceived as 'challenging' and impinge on family relationships and functioning.

The impact of challenging behaviour is investigated in terms of parent and family stress. The nature of stress is defined in terms of objective and subjective strains, which are outlined. Alleviation of stress/strain is proposed as a goal for intervention.

Parent-training for behaviour management is introduced as the method of intervention. The history of parent-training is outlined briefly and the implication of parent-pathology or 'blame' underlying the need for parent-training is investigated. Assumptions purported to underlie parent-pathology are identified and challenged.

Particular attention is paid to the role of attributions in defining challenging behaviour. The effect of the mood of the observer on attributions and subsequent interactions with the child with challenging behaviour is examined and the information proposed to be inherent within occurrences of challenging behaviour is outlined. The salience of challenging behaviour associated with the condition of

ASD is hypothesised as a basis for parent perceptions of the child, parent attributions about behaviour and subsequent behaviours towards the child. A caution is noted about the influence of culture on attributional research and the idea of being able to change attributions by evoking an empathetic understanding is broached.

Child behaviour is considered in terms of a 'systems' approach and the impact of community, societal and cultural systems on the family with a child with ASD in a New Zealand context are examined. Particular attention is given to the New Zealand culture and challenging behaviour is examined within Māori and non-Māori culture. An explanation for under-representation of Māori in New Zealand ASD statistics is proposed. The practice and extent of parent-training and parental involvement is outlined and 'parent-training' as an intervention technique in this study, is outlined.

The next part of the introduction focuses on the *content* of the proposed parent-training programme. Behaviour analysis and applied behaviour analysis (ABA) are outlined from historical viewpoints and with relevance to the field of ASD. Current utilisation of ABA concepts are outlined and the impact of 'ABA' programmes on the family with a child with ASD are examined.

Applied behavioural analysis (ABA) is introduced as an approach to managing challenging behaviour associated with ASD. A brief history and outline of a functional emphasis to ABA is followed by an exposition of the benefits of this approach over other traditional behaviour analysis techniques. Limitations of the ABA approach when applying techniques to ASD are proposed.

Theory of Mind (ToM) is identified as a potential alternative approach to managing challenging behaviour associated with ASD. ToM is defined and outlined with reference to previous research and models. Features of ASD in the three core areas – socialisation, communication and restricted interest/cognition are revisited in the light of ToM and daily life without a complete ToM is considered. ToM is defined as a 'mentalising' problem and previous efforts to teach ToM are outlined. Clarification of ToM concepts allows consideration of

developing a parent-training component aimed at enhancing parent social understanding and helping parents to see the world of the ASD through their child's eyes. Aiding development of an empathetic response is proposed to favourably alter parent behaviour, attributions and beliefs and help parents to formulate behaviour management strategies aimed at reducing the challenging behaviour associated with ASD. A summary of introductory themes and research aims concludes the introductory chapter.

A methodology section (Chapter 2) outlines participant details and selection criteria. Group assignment is detailed and single-case research is outlined as the experimental design of choice. Statistical procedures are briefly outlined and programme content is detailed. Measures are described and the procedure of measurement and recording is outlined. The last part of this chapter provides an overview of the following results sections.

The results section (Chapters 3-8) forms a major part of this research. Chapters 3 & 4 focus on child behaviour outcomes. Parent outcomes are the focus of Chapter 5 & 6 and family stress outcomes are examined in Chapter 7. Chapter 8 is an evaluation chapter, which considers the views and comments of parents-participants for programme, content, length, behaviour change validity and group format. Each results chapter contains detailed results of outcomes and discussions about findings. Limitations or future research proposals are contained within each chapter.

Chapter 9 presents the conclusions of this study and contains a summary of all results chapters. Results are discussed with reference to research aims, limitations of the study are examined and research findings are concluded.

The Appendices contain all relevant participation forms, record forms, interview and evaluation forms. A copy of the attribution rating scale developed for this research and a trainer-copy of the nine-week programme utilised in this study are included.

CHAPTER 1

Introduction

Autistic Spectrum Disorder

In the 1940s, two paediatricians on opposite sides of the world described groups of children with three common characteristics: poor social interaction, communication difficulties and restricted range of interests or behaviours. In the United States, Leo Kanner (1943) described a group of children who exhibited an inability to develop relationships; delays in language acquisition or non-communicative use of spoken language; resistance to change and stereotyped/repetitive play. In Austria, Hans Asperger (1944) described a group of children who shared similar core features but who were comparatively both cognitively and verbally skilled. Due to language and translation difficulties, Kanner's description dominated the diagnostic literature for the following 40 years. Children who met the descriptive criteria became known as having 'Kanner's autism', 'classic autism' or 'early infantile autism'.

In 1981, Lorna Wing reintroduced Asperger's original description. This condition, which became known as 'Asperger's Syndrome', tended to be used to describe children with core symptomatology and high functioning skills. Spurious use of the diagnostic criteria to refer to functional abilities and skills has meant that the diagnosis of Asperger's Syndrome has been (and still is being) erroneously applied as a diagnostic description (e.g., Miller & Ozonoff, 1997) for those children with autism who also have speech or language ability.

The distinction between these two groups of individuals with autism tends to dominate current thinking today. Professionals and parents alike continue to refer to Asperger's as the 'milder' form of the autistic condition. Major diagnostic manuals (e.g., Diagnostic and Statistical Manual of Mental Disorders, 4th ed., text revision - DSM-IV-TR, American Psychiatric Association, 2000; International Classification of Diseases and Related Health Problems - ICD-10, World Health Organisation, 1992) continue to recognise both conditions (Autistic Disorder and Asperger's Disorder) separately. In the DSM-IV-TR, both conditions come under

the umbrella of Pervasive Developmental Disorders (PDD) which are characterised by severe and pervasive impairments in several areas of development. Other conditions that are contained within this grouping include Rett's Disorder, Childhood Disintegrative Disorder and PDD – not otherwise specified (PDD-NOS).

The fact that a distinction exists between Autism and Asperger's Disorders continues to be the cause for major debate (e.g., see Howlin, 1998; Ozonoff, Rogers, & Pennington, 1991). In 1988, Lorna Wing introduced the concept; 'Autism Spectrum Disorders' (ASD), an expression which includes both Kanner's and Asperger's subgroups. The concept of a *spectrum* of autism expression or behavioural topography is most important and emphasises the continuum of abilities and presentations inherent within the condition. The term ASD, will be utilised throughout the rest of this thesis to denote the autistic condition. Individuals with ASD share common core features often referred to as the 'autistic triad' (socialisation, communication and imagination) or 'triad of impairments' (Wing & Gould, 1979) signifying difficulties with socialisation, communication and imagination (Siegel, 1996). They also exhibit a remarkably diverse and unique presentation of these core features and abilities. In fact, autism is the most wide ranging developmental condition that is currently known (Lawson, 1998).

The diverse manifestations of behaviours and abilities associated with ASD have led to considerable debate over accurate diagnosis and prevalence estimates. Originally considered rare, current UK estimates of the prevalence of Autism Spectrum Disorder are in the vicinity of 91 persons per 10,000 population or approximately one percent of the population (Autistic Association of New Zealand Inc (AANZ), 1998; Wing, 1996). Conservative estimates reveal that around 35,000 to 40,000 individuals in New Zealand are functioning within the autism spectrum. It is estimated that the majority (78%) of these individuals have 'high functioning' abilities, i.e., average or above average general abilities (AANZ, 1998).

Higher functioning individuals are generally diagnosed much later than individuals displaying more 'classic' symptoms and thus it is possible that the

majority of people with an ASD may not have been diagnosed (Attwood, 1998; Howlin & Moore, 1997). Moreover, the range of behavioural manifestations accompanying the core features have often led to *misdiagnoses* including attention deficit with hyperactivity disorder (ADHD), schizophrenia, anxiety and mood (depression) disorders. Individuals with ASD functioning at the higher end of the spectrum are often observed to exhibit behaviours that may place them at an interface with 'normal' behaviours. Viewed in any single environmental context, their behaviour may have an unusual presentation. However, a lack of distinctive or disruptive features may escape undue notice and dissuade active investigation. Such individuals may be considered odd, loners, socially inept, or eccentric. Consider a description by Attwood (1998), when describing the higher functioning child with an ASD in the classroom:

> ...the child's first teacher is familiar with the normal range of behaviour and abilities in young children and becomes concerned that the child avoids social play, does not understand the codes of social conduct in the classroom, has unusual qualities to their conversation and imaginative play, an intense fascination with a particular topic...
>
> They can also be disruptive or aggressive when in unavoidable proximity to other children, or having to wait. At home, the child may be almost a different character, playing with siblings and interacting in a relatively natural way with their parents. In unfamiliar circumstances, however, and with their age peers, the signs are more apparent.
>
> These children have the classic signs but are often not considered by teachers as a priority for referral to diagnostic agencies. They are viewed as odd children, continuing through school and leaving each of their teachers perplexed (Attwood, 1998, p.24).

When prodigious abilities or savant skills are observed (e.g., precocious musical talent or mathematical genius), accompanying oddities of behaviour are commonly dismissed as being an inherent part of giftedness or as a result of the intense focus required to gain excellence in a particular skill or ability thereby leading to further diagnostic confusion.

In summary, individuals within the 'autism spectrum' of disorders display a wide variety of presentations ranging from severe cognitive, behavioural and language impairments to 'high functioning' or even 'gifted' abilities. Diagnosis of autistic

conditions remains challenging. However, while the recognised criteria for diagnosis continue to undergo modification, ASD is ultimately considered to represent a continuum of behaviours that encompass impairments in three core areas: social relationships, social communication and a truncated range of activities and interests.

Causes

It will be apparent by now that ASD is not a specific unitary condition and as such, neither does it have one clearly defined cause. Instead, ASD is a heterogeneous behavioural syndrome found in association with many causes including genetic factors, viral/infections and injury (Aaron & Gittens, 1992; Attwood, 1998; Gillberg, 1992; Locke, Banken, & Mahone, 1994; Pelios & Lund, 2001; Sigman & Capps, 1997). While a single causal factor has not been identified to date, it is generally accepted that the causal mechanism has a neurobiological effect on the brain. The specific site and type of brain dysfunction have not been clearly elucidated but the research in this area is gaining momentum. For example, in February 2002, scientists found higher quantities of cell microcolumns in the frontal and temporal lobes of individuals with ASD (British Broadcasting Corporation - BBC, 2002). Regardless of the theoretical speculation about underlying causes and neuropsychological dysfunction, the triad of impairments constitutes a core set of behaviours upon which the diagnosis of ASD is made.

Core Features of ASD

Each of the three core features of ASD will be examined in some detail in this section in order to set the background for the theories and resulting interventions currently used with individuals with ASD.

Socialisation. Social impairment in ASD is characterised by a failure to develop the behaviours that allow individuals with ASD to engage in social and mutual interactions with others. This feature is manifest in behaviours that include marked impairment in the use of nonverbal behaviours such as eye contact, facial

expression and body posture/proximity to regulate social interactions; a failure to develop peer relationships appropriate to developmental level; a lack of spontaneous seeking to share enjoyment, interest or achievement with others; a lack of social or emotional reciprocity; a lack of empathy or insensitivity to the feelings of others, a preference for isolated/solitary play and a failure to appreciate the demands of social situations leading to inappropriate behaviour in public settings (e.g., Attwood, 1998; Gillberg, Nordin, & Ehlers, 1996; Rimland, 1994; Wing, 1996). Individuals with ASD appear to have no concept of the 'need' for others and those who are interested in friendships lack the conventions of social understanding:

> She drifted towards solitary spaces: the corner of a room, behind the curtains, behind the armchair. If I was somewhere else in the apartment, she never sought me out but would spend hours just manipulating a toy or poking at the rug (Maurice, 1993, p. 31).

Differences in the quality and frequency of interactions with other people often produces a confusing picture. Some children with higher functioning abilities often seem to interact in a socially competent manner with adults. Koegel and colleagues (Koegel, Koegel, Frea, & Freden, 2001) suggest this may be due to adults often being the initiator and providing a highly responsive and often anticipatory social environment. In contrast, they propose that high-functioning children do not appear to interact at an age-appropriate level with other children because child-child interactions require effective and reciprocal participation by both parties.

In her book, *Life Behind Glass,* Wendy Lawson describes the mystery of social interactions from the perspective of one diagnosed with Asperger's Syndrome:

> I find emotions interchangeable and confusing. Growing up, I was not able to distinguish between anger, fear, anxiety, frustration or disappointment. To an autistic person, kindness, affection and intimacy are confusing because they do not seem to have a purpose; sometimes it is tempting to think that maybe that is their purpose. Emotions are not concrete structures that can be seen, held or organised. They can be likened to being locked in a maze with no exit; all paths look the same and lead to the same place. This place is very confusing and will often cause fear and even terror in an autistic person (Lawson, 1998, p. 8)

Communication. Communication difficulties can include language delay or absence of spoken language, age-inappropriate echolalia, pronoun reversal and confused relationships between objects and time. Individuals with ASD can exhibit stereotypy or parroting of speech resulting in flat pitch, tone or affect. They tend to lack humour and fail to utilise non-verbal cues. Speech is often characterised by short demands, idiosyncratic use of words and restricted grammatical variants (e.g., Howlin, 1998). They have a literal interpretation of metaphors, verbal shortcuts and abstract language. Story-telling and language is often truncated compared with same-age peers and devoid of causal connections (Bruner & Feldman, 1993; Tager-Flusberg, 1993, 1995).

Communication deficits are commonly characterised by a failure of children with an ASD to use speech for social communication or interaction (Wing & Attwood, 1987). Parents often have believed their children to be deaf as they have shown no response to their name, greetings, requests or communications from others. The child with ASD leads people to objects they desire rather than articulating their needs:

> There was no 'connection' with other human beings. I seemed no more important to him than a chair. He used my hand like a tool to pull open the refrigerator door for juice, as though the rest of me was just an unimportant accessory to the hand (Sullivan, 1992, p. 247).

> She seemed to have almost no nonverbal communication. No smile, no nod, no head shake, no gesturing or shrugging or mimicking of facial expressions...If she wanted something – a toy, a piece of food, a bottle – she would take the nearest adult's hand by the back of the wrist, never looking up while she did so, and shove it at the desired item (Maurice, 1993, p. 33).

Those *with* verbal ability often fail to use it to interact with others leading observers to inaccurately conclude that the child is callous, insensitive or deliberately shunning others (e.g., Howlin, 1998). They show a marked impairment in the ability to initiate or sustain conversation with others. Those with advanced language skills may perseverate on particular topics without regard to the interest or cues of the listener.

Imagination/cognition. Interests tend to be restricted and behaviours are often perseverative, stereotyped or ritualised (e.g., Strain, 1990). There is a marked resistance to change or alteration of routine and environment. Individuals with ASD can be observed to engage in seemingly meaningless activities for excessive periods of time:

> She would stare at a piece of dust, then slowly bring it up in front of her eyes and gaze at it, enthralled. She pulled little pieces of string off the rugs or the furniture, or a hair out of her doll's head. These she would twirl between her fingers, endlessly fascinated (Maurice, 1993, p. 40).

Wendy Lawson, an individual with ASD, gives an interesting insight into some of those activities. She describes feeling exhilarated by colour, shape and movement and even as an adult, she would watch events unfold with little consideration of the time involved or the cues from other people (and events) around her:

> ...I noticed how calmly the water washed over the grains of sand and pulled them back into the sea as it retreated. The movement of constant washing, pushing forward and retrieval fascinated me and I could watch it for hours.
>
> ...I noticed some movement at my feet and saw the last exit moments of a cicada crawling out of a hole in the ground. I watched this creature transform before my eyes from a dull brownish-green bug into a beautiful bright green and gold, singing creation. The process took only one and a half hours [on a public footpath] (Lawson, 1998, p. 115).

Children with ASD and their typically developing peers play with a comparable number of stimulus items but those with ASD have been observed to engage for shorter duration and spend less time 'on-task' (Koegel, Koegel, Frea, & Freden, 2001). Non-functional play is often observed as an obsessional or unusual attachment to objects or aspects of objects:

> Toys did not interest him, or if he did play with them, it was not in the way they were meant to be used. He would spin a wagon wheel for hours at a time if we didn't intervene, often laughing ecstatically – incomprehensively and eerily entertained (Sullivan, 1992, p. 248).

> He liked the idea of taking something to bed with him but shunned the teddy bear in favour of teaspoons, hairbrushes and other inanimate and non-cuddly objects (communication with mother of 5 year old boy with high-functioning autism).

Individuals with ASD display difficulty engaging in imaginative play or activities in the absence of visual modelling/examples and a failure to imitate the social behaviours of others (Stone, Ousley, & Littleford, 1997). Lovaas and colleagues (Lovaas, Schreibman, Koegel, & Rehm, 1971) use the term 'stimulus overselectivity' to describe the observation that children with ASD tend to respond to a single (usually irrelevant) feature of a compound stimulus. While not unique to the area of ASD, stimulus overselectivity provides some explanation of abnormal patterns of perception and attention, idiosyncratic and stereotypical interactions with the environment and difficulty with shifting attention.

Other researchers have offered further features they believe are central to the condition of ASD. Attwood (1998), for example, adds a fourth feature - sensory sensitivity. Wendy Lawson gives the following account:

> I always need to be on the move. Even when I was made to sit still on a chair, I had to rock it. If I sat on the floor, I needed to rock myself and suck the roof of my mouth – the rhythm and the movement meant I was alive and kept the music going. I think I believed that if I ended the movement, then that would be the end of me (Lawson, 1998, p. 24).

However, while individuals with ASD clearly have aberrant responses to a variety of sensory input (e.g., Grandin, 1995a), research has not supported the existence of perceptual deficits unique or necessary to the diagnosis of autism (Frith, 1991; Teunisse, Cools, van Spaendonck, Aerts, & Berger, 2001). In fact, studies indicate excellent functioning of basic perceptual processes (Frith & Baron-Cohen, 1987) and thus it is suggested that higher level or *central* cognitive processes (as opposed to *peripheral* processes) may be dysfunctional in ASD leading to difficulty utilising context and interpreting stimuli as meaningful (Happé, 1999).

The challenging behaviours associated with ASD

The core features of ASD consist of a variety of behaviours in three key areas. Each behaviour has the potential to be viewed as challenging for the family living with a child with ASD. For example, resistance to change, repetitive/obsessive behaviours, a lack of language and social communication/awareness, aggression, self-stimulating/mutilating behaviours, motor clumsiness, restricted repertoire of interests/activities and sensory/perceptual impairments are common features of the ASD condition. While isolated incidents of challenging behaviour may be considered typical in normal child development, the range of behaviours inherent within ASD are pervasive and persistent throughout the lifespan of the individual. A diagnosis on the autism spectrum indicates that the individual exhibits a number of distinct and significant behaviours in each area of the 'triad of impairments' and these behaviours occur in multiple domains at the same time.

From the parent's view point, children with ASD present a perplexing picture. They are both present and yet apart from the family and familiar social contacts. They approach others and yet remain somehow distant:

> There she moved, every day, among us but not one of us, acquiescent when she was approached, untouched when we retreated, serene, detached, in perfect equilibrium. Existing among us, she had her being elsewhere (Park, 1992, p. 12).

Parents struggle to understand their child's actions and attempts to communicate. They are shocked or disquieted by the bizarre and ritualistic behaviours displayed and often are bewildered by the sheer force and duration of behavioural outbursts that appear to occur often without reason or provocation.

Parent Stress

Investigations have shown that parents of children with ASD face higher 'stress' levels than parents of children with almost any other disorder (Bitsika, Sharpley, & Efremidis, 1997; Burke & Richdale, 1997; Hastings & Johnson, 2001; Sanders & Morgan, 1997) yet despite the increase in professional knowledge in the area of

ASD, *parents* of children with ASD are themselves a relatively unstudied group (Lawson, 1998). Parenting stress is the stress perceived by the parent as occurring within the role of parenting. It is comprised of stress from both child and parent characteristics (Abidin, 1990).

Parents are usually unprepared for the range of demands that accompany the child with developmental disabilities and often have no prior knowledge or experience available from which to draw (Siegel, 1996; Solnit, 1989). Coping with a child with developmental difficulties often requires lifestyle and personal changes for the family (Elksnin & Elksnin, 1994) which increases the potential for stress and decreases parenting self-esteem and efficacy (Johnston, 1996). There is considerable evidence that suggests that having a child with a disability places stress on marriages, siblings and extrafamilial members (e.g., Gargiulo, 1985; Hornby, 1987). In general, mothers of children with disabilities show significantly more stress symptoms than fathers (Moes, Koegel, Schreibman, & Loos, 1992; Padeliadu, 1998). This is assumed to be a reflection of the different gender responsibilities assigned to child rearing, i.e., the mother is often the primary caregiver and spends more time parenting the child and being engaged directly in child-care duties. The following section deals with the nature of stress in relation to parenting a child with special needs and developmental difficulties.

The Nature of the Stressors

The demands of living with, parenting and caring for a child with special needs or challenging behaviours are profound and impinge on many areas of family functioning (Emerson, 1995; Howlin & Rutter, 1987; Moreno, 1992; Wolf, Noh, Fisman, & Speechley, 1989). In a comprehensive study working with children with mental, emotional and behavioural problems, Brannan and colleagues (Brannan, Heflinger, & Bickman, 1997) identified three separate and unique dimensions of strain that affect primary caregivers:

Objective

Subjective – internalised

Subjective – externalised.

These three classes of strain are not mutually exclusive. Any one component of strain may influence (exacerbate or lessen) the effect of another component and different dimensions may assume importance at different life stages of the individual and/or family. Each will be examined in some detail with application to the area of ASD.

Objective Strain

Objective strain refers to the observable occurrences resulting from the child's condition. They include financial strain, interruptions to personal time and social isolation.

Financial strain.

Various financial difficulties can arise in the family of a child with special needs and can be either direct (e.g., seeking available therapies, professional/specialist fees, specialist learning aids/equipment) or indirect (e.g., the loss of an income due to inappropriate or inaccessible alternate care arrangements or educational facilities). The cost of therapies available to families with children with ASD vary widely. In New Zealand, primary care is provided free of charge in the health and education sectors. However, individual therapies and training programmes range from professional consultation fees to thousands of dollars for access to overseas-based treatment programmes or education programmes not eligible or approved for government funding.

Interruptions to personal time.

Caregivers of children with special needs have significantly more time demands than parents of children without special needs (Erikson & Upshur, 1989; Turnbull & Turnbull, 1990) and the increased time demands are significantly correlated with increased reports of stress. Not surprisingly, caregivers' assessment of the time spent engaged in extra tasks has been found to mediate the reported stress experience. Thus, those caregivers who rated tasks as 'enjoyable' or 'fun' (e.g.,

educational activities) reported less stress while those who rated tasks negatively or resented doing them (e.g., extra cleaning, incontinence) reported more stress (Padeliadu, 1998).

Due to the nature of the core deficits in ASD, parents are required to use more reminders, prompts, direction, monitoring and encouragement to maintain the child's attention and learning. The skills other children learn through social interaction and observation have to be shaped in the child with ASD (Schreibman, 1988). Such training must be repetitive and occur in a number of different situations to facilitate generalisation to other settings. Common situations and events often have to be explained and routines developed in order to reduce anxiety and parents have to remain constantly vigilant to potential setting events in the daily activities of the family. In addition, individuals with ASD often do not require much sleep (e.g., Williams, 1992) causing disruption and sleep deprivation for others.

Social isolation.

Social isolation may occur directly as a result of the child's behaviour or indirectly through the parents own coping resources or perceived societal expectations (Gill & Harris, 1991; Howlin, 1998). Frequent tantrums, outbursts of aggression, self-stimulatory behaviour, lack of social responsiveness or reciprocity, obsessive interests and a lack of approach towards others are typical ASD behaviours and do not facilitate positive social interactions with others. Moreover, unfamiliar people or settings often exacerbate the child's anxiety making such behaviours more pronounced. A poor understanding of ASD by others continues to contribute to a marked antipathy for the typical behaviours displayed by these children (Sharpley, Bitsika, & Efremidis, 1997). Parents often feel obliged to apologise or attempt to explain their child's behaviour which may be viewed as disruptive, antisocial, irresponsible or age-inappropriate. A lack of appropriate alternative support or active avoidance by alternative caregivers, who feel unable to deal with the child's behaviour, may lead to parents being unwilling or unable to engage in social activities outside the home (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001).

Social support as it pertains to families with children with ASD is not confined merely to the availability of accepting 'others' within the family's milieu. Rather, 'social support' has been defined as the perception (by the parents) that others (particularly family members and alternative caregivers) have a clear understanding of the child's condition and needs (Sharpley et al., 1997; Singer, Irvine, & Irvin, 1989). This clear expectation has positive implications for the development of educational programs to alleviate social isolation for families with individuals with ASD (Bristol, Gallagher, & Holt, 1993). It has been proposed that such social support can develop from relationships with other parents/caregivers who share similar and can occur in a group environment (Hornby & Singh, 1983; Niccols & Mohamed, 2000; Webster-Stratton, Kolpacoff, & Hollinsworth, 1988).

Subjective Strain

Internalised. This dimension of strain is associated with feelings that are internalised by the caregiver. Such feelings include sadness or concern about the future, concern over the perceived emotional toll exacted on other family members, general despondency/hopelessness about the condition, beliefs about own parenting abilities and parenting efficacy:

> I resented the change away from the ordinariness I craved. The dual life we lived, moving between normality and specialist attention, had a crazy pattern all of its own, and we were often reluctant players (Brown, 1994).

Koegel and colleagues (Koegel, Schreibman, Loos, Dirlich-Wilhelm, Dunlap, Robbins, & Plienis, 1992) found that concerns about the child's future, the ability of the child to function independently and levels of cognitive/ linguistic impairment were consistent among parents of children with ASD regardless of the age of the child, their functioning level, geographic location or culture. Specifically parents were worried about how these factors would enhance or impede acceptance into the community and/or the elicitation of care from others.

When faced with the permanent and pervasive nature of ASD, a lack of social responsiveness/feedback from the child, and a general lack of understanding by social networks and the greater community, it is not surprising that parents can become despondent (Banister, Burman, Parker, Taylor, & Tindall, 1994). Depression is more predictive of long-term adjustment in families with a child with a developmental disability than demographic factors including maternal education and family income/resources (Glidden, Kiphart, Willoughby, & Bush, 1993).

Parents initially have a propensity to experience guilt/self-blame over the lack of social responsiveness of the child. A perceived 'failure' to effectively manage behaviour concerns can lead to doubt about parenting abilities and a disbelief in the efficacy of their actions resulting in low parental self-esteem, decreased functioning and increased perceptions of stress (Attwood, 1998; Bandura, 1982; Johnston, 1996; Jordan & Powell, 1995; Moes, Koegel, Schreibman, & Loos, 1992). When faced with persistent, unpredictable challenging behaviours without the resources to effectively move forward, parents have been shown to use more negative reactions and fewer positive parenting strategies (Johnston, 1996).

Externalised. This dimension of strain is associated with negative feelings from the caregiver that are directed towards the child. For example, socially inappropriate behaviour is seldom the cause of embarrassment when a child is aged two years. However, the same behaviour exhibited in a 22 year old may cause significant stress and social isolation. A perception that a child deliberately fails to follow instructions may lead to anger and demands on personal time may lead to resentment. Negative feelings and reactions are exacerbated when behaviour results in increased cleaning-up effort (e.g., breakages, mess), when the caregiver has to physically intervene or has to spend time calming others down (Bromley & Emerson, 1995).

In summary, the stressors on families with children with ASD are many and varied. They persist throughout the lifespan of the individual and family and often change in emphasis as development progresses. Stressors exist on both an

objective and subjective basis and affect the parent-child relationship and interactions within the wider family, social networks, community and society.

Alleviation of Stress as an Intervention Goal

The identification of potential areas of stress has important implications for the development of treatment programmes aimed at working with families with children with ASD (Brannan et al, 1997; Powers, Singer, Stevens, & Sowes, 1992). The key goal to intervention in such families has been to enhance child development and functioning. There is an implicit assumption that such child-focused intervention will result in benefits to the family in the form of decreased stress. For example, modifying challenging child behaviour would be expected to alleviate family stress by decreasing the amount of time demands on caregivers and allowing increased opportunities for engaging in activities outside the home (Koegel et al, 1992). Most intervention efforts to date have been derived from a child focused, directive teaching framework. Such a focus fails to consider the area of subjective strain by failing to involve the caregiver in the intervention process. While some concerns about child functioning may be alleviated with successful intervention, caregivers' beliefs in their own parenting ability and efficacy are often worsened due to the fact that someone external to the parent is seen to be both necessary and able to effect positive change in their own child's life. A failure to provide the caregiver with the skills and techniques necessary to manage challenging behaviours results in limited treatment gains and/or a failure to maintain developmental gains outside of the intervention process (e.g., Koegel, Glahn, & Nieminen, 1978; Sanders, 1992) thereby increasing subjective strain once again.

An intervention approach that enhances parental efficacy and competence as well as seeking to modify child behaviour would be expected to result in decreased subjective stress and increased report of parental confidence and effectiveness. Such an approach is inherent within the field of parent training and will be discussed shortly. Before concluding this section, two extenuating factors need to be noted. Firstly, the above stressors have been identified within a cultural context and to date there is little information concerning the universality of stress

experiences between different cultures/societies. Secondly and importantly, it is erroneous to believe that all interactions involving the child with ASD are fraught with difficulty and stress. On the contrary, family members also report enriched lives through caring/sharing with the child with ASD (Jordan & Powell, 1995).

Parent Training for Behaviour Management

History

From a dominant and traditionally unidirectional model of therapist-client interaction, the introduction of parent training in the 1970s represented a profound paradigmatic shift in therapy administration (Graziano & Diament, 1992). From an intense interest in the internal motivation of the child, the focus of parent training intervention moved towards an emphasis on the role of the *parent* as a significant contextual variable within the child's environment (Lovaas, 1978; Mahoney, Spiker, & Boyce, 1996). In effect, treatment focused on training parents to modify their parenting behaviour in order to effect change in child behaviour.

Over the past 30 years a large body of literature has demonstrated the effectiveness of parent training in modifying children's problem behaviour. For reviews and examples in this area, the reader is directed to Berkowitz & Graziano, 1972; Draper, Larsen, & Rowles, 1997; Forehand & Long, 1988; Graziano & Diament, 1992; Kazdin, 1985; Long, Forehand, Wierson, & Morgan, 1994; McCollum & Hemmeter, 1997; McMahon & Forehand, 1984; Rogers-Wiese, 1992; Sanders & James, 1983; Todres & Bunston, 1993). Parent training has been successful in altering a number of behaviours associated with specific conditions (e.g., non-compliant/oppositional behaviours, Serketich & Dumas, 1996; conduct disorder, Webster-Stratton, 1984), over a wide range of ages (Ruma, Burke, & Thompson, 1996) and over long time periods (Schreibman, 1988).

Including parents in a family-oriented approach to child problem behaviours has resulted in practical benefits for the therapist in terms of therapeutic intervention (e.g., access to social interaction factors, environmental contingencies), outcomes (e.g., generalisation) and ethical considerations (e.g., informed knowledge of

treatment mechanisms and outcome measures/expectations). There have also been benefits for the parent in terms of overcoming financial/time constraints and limited access to professionals (Berkowitz & Graziano, 1972; Herbert, 1995; Sanders & Dadds, 1993; Webster-Stratton, 1992). Significant benefits have also been noted for families in terms of decreased stress, improved parent-child relationships, increased parental affect and improved family relationships (Kaiser, Hemmeter, Ostrosky, Fischer, Yoder, & Keefer, 1996; Koegel, Bimbela, & Schreibman, 1996; Mahoney, Kaiser, Girolametto, MacDonald, Robinson, Safford, & Spiker, 1999).

While the merits of parent training programs are extensive, the development and practice of parent training has not been straightforward. In fact the upsurge of interest and research applications of parent training has inadvertently contributed to the confusion by perpetuating unsubstantiated rationales underlying intervention. Most notable is the persistence of parent 'pathology' or blame.

The Genesis and Legacy of Parent 'Pathology'

Prior to the introduction of parent training, the dominant therapeutic attitude towards parents was either benign (i.e., parents were deemed to be unnecessary to interaction and therefore ignored) or accusatory (i.e., they were regarded as the source of conditioning history - Dumas, 1986). Unfortunately, in the area of ASD, this latter attitude gained dominance in causative speculation. When Kanner (1943) first described autistic symptomatology – he also noted parents (particularly mothers), appeared to be cold, emotionally distant and aloof. Psychoanalysts at the time grasped this explanation to explain the occurrence of autistic behaviour (e.g., Bettelheim, 1967; Ferster, 1961). Although this 'refrigerator parenting' hypothesis was not empirically supported (e.g., National Society for Autistic Children, Board of Directors and Professional Advisory Board, 1977 in Turnbull & Turnbull, 1990) and lost favour with the application of behaviour modification theory, there remains a disconcerting remnant of 'parental pathology' in the literature today (e.g., conversational deprivation in early development environment of children with autism – Peterson & Siegal, 2000).

Parent training programs often refer to the need to teach parents 'appropriate responses' to their child's behaviour which immediately implies that they have some 'deficient', 'inefficient' or 'inappropriate' child management skills. Further, such parent training programs are developed because families present with a child (or several children) who exhibit difficult behaviours. One implication here being that children who do not exhibit such behaviours are the result of parents who are able to parent 'effectively' – a sentiment that is inadvertently reinforced when researchers choose to compare such groups to control groups comprised of non-problem behaviour children (e.g., Johnston & Freeman, 1997). Other researchers are more forthright and refer directly to attempts to improve parent behaviour citing parent subjects as 'inconsistent' (Dumas & Wahler, 1983), 'disorganised' (Berkowitz & Graziano, 1972) or 'power assertive and lax in their discipline' (Dumas, Lafreniere, Beaudin, & Verlaan, 1992). In the majority of these cases, *parent* pathology is purported to account for errant child behaviour and therefore becomes the 'target' of parent training programs. One rationale for such an approach can be found in basic behavioural theory.

Behaviour theory maintains that if an emitted behaviour elicits a favourable response from the environment, then it is likely to be maintained or increased. On the other hand, if the elicited environmental response is aversive or negative, the emitted behaviour is likely to decrease or cease. Child behaviour can be conceptualised as a function of the contingencies of reinforcement and punishment encountered in the course of daily interactions with their environment. Parents, as potent social agents in their childs' environment, deliver both positive and negative learning contingencies which both shape new learning and maintain previous learned behaviour. Parent behaviour is therefore viewed as an important set of contingencies that shape, reinforce and maintain child behaviour (e.g., Schopler, 1978). If child behaviour is dysfunctional or aberrant, the reinforcement contingencies (i.e., the parent's behaviours) are also assumed to be dysfunctional or aberrant. It is noted that other significant caregivers, extended family/whanau members, siblings, peers and teachers also have an impact on the learning environment of any given child, however, the focus of this research is the *parent* or primary caregiver.

The key to parent training is to change child behaviour by changing parental reinforcement contingencies (e.g., Todres & Bunston, 1993). In practice, this training emphasises 'consequence based' child management skills by encouraging the parent to monitor behaviour and apply contingent rewards and effective punishments (also known as 'contingency management – Berkowitz & Graziano, 1972). Such therapeutic endeavours rest on a number of implicit assumptions that may or may not be substantiated. For example, the contingencies maintaining problematic behaviour in the child's environment are assumed to be under parental control and the parent is assumed to have access to these contingencies at all times. The provision of contingency 'skill' training is assumed to equip parents to alter child behaviour. Finally, the relationship between the parent and child is assumed to be simple and dyadic. Each of these assumptions will be considered in further detail here.

Assumption 1: Contingencies maintaining problem behaviour in the child's environment are largely under parental control. If the child is preschool aged, one could possibly assume that the parents have an increased ability to influence the child's environment. However, with New Zealand following overseas trends, the number of families with both parents or single parents working outside the home is on the rise (Maxwell, 1991). Young children are commonly exposed to creche/childcare facilities, preschool environments and extended family care arrangements (Edgar, 1991; Hassall, 1991; Social Advisory Council, 1987). Moreover, with the changing emphasis of family composition in New Zealand to include single parent families and alternative care arrangements, not only is it doubtful that child behaviour is necessarily under 'parental' control but the assumption that the child's environment is dominated by the parents is also questionable.

Not only are behavioural contingencies assumed to be within the parents' sphere of influence but errant child behaviours are also assumed to be a direct result of parents non-use or misapplication of these contingencies. As the following illustration (based on a real case example) shows, a common attribution by others when faced with a situation of unexplained disruptive behaviour is that the parent/s fail to adequately address discipline issues.

Joey (aged 4 years) has a pattern of escalating violent behaviour towards other children in his preschool setting. Joey is an only child and has shown no animosity towards other children in his home environment. Adults in the preschool believe that Joey's behaviour is the result of lax expectations and ill-defined limits at home. A 'time out' procedure fails to alter Joey's behaviour and heightens both the perplexity and tension of the preschool staff and Joey's mum.

We will return to Joey later, but needless to say, the assumption that reinforcement contingencies are accessible to the parent and under parental control, remains speculative.

Assumption 2: Provision of skill training can equip parents to alter child behaviour. Skills training programs or 'packages' seek to influence child behaviour by enhancing parental understanding and management skills. Once trained, one could assume that parents now have the means to change child behaviour. However, research has identified a number of confounding factors that have been found to affect the administration and application of parent training information. These factors include the *ability* of the parent to receive training, the *method* of training and the *application* of training received. A number of factors affect parental ability to benefit from skills training e.g., emotional state, marital relationship, spousal support, level of extrafamilial support and the presence or absence of other life stressors (Dumas & Wahler, 1983; Howlin & Rutter, 1987; McMahon, Forehand, Griest, & Wells, 1981; Reuter, Conger, & Ramisetty-Mikler, 1999; Sanders, 1984; Wahler, 1980). Process issues including therapist-client relationship (Sanders, 1992) and the mode of skills training presentation also affects results (Webster-Stratton & Herbert, 1993). For example, Webster-Stratton (1992) found that gender issues influenced outcomes when parents undertook a self-administered video training program. Mothers who were partnered, had high mental ages and low levels of depression were found to benefit from training while the same applied to fathers who had a combination of low depression, low mental age and low life stress. Finally, provision of training does not necessarily mean that a particular application is adhered to and as shown

in Joey's case, even when administered, behaviour change may not necessarily follow.

Assumption 3: The relationship between parents and children can be conceptualised as simple and dyadic. Most parent training literature implies a simple unidirectional relationship between the child and his/her parent/s. The child is viewed as the change target and the parent is viewed as the change agent (Todres & Bunston, 1993). In other words, the child behaves (or rather, *mis*behaves), the parent exerts influence on the contingencies maintaining the behaviour and the child's behaviour changes. As can be appreciated by now, the relationship between parent and child is far from simple. The basic premise that parents can be trained to modify child behaviour fails to take into account the fact that child behaviour also affects parent behaviour in a cyclical manner (Barnard, 1997; Lerner, Castellino, Terry, Villarruel, & McKinney, 1995). In particular, child behaviour has a significant effect on the parent's cognitive behaviour including attributions, self-belief and parental efficacy. Challenging behaviours have the potential to negatively affect the parent/child relationship. Similarly, intervention aimed at managing challenging behaviours will also be expected to have a positive effect on parent behaviour and cognitions (Campbell, Goldstein, Schaefer, & Ramey, 1991). We digress at this point to consider the relationship between attributions and behaviour in more detail as the challenging behaviours which are a focus of this study have significant implications for the relationship between parent/caregiver and child.

Attributions and Behaviour

Attributions and behaviour are linked in a dynamic bidirectional interaction: attributions can affect behaviour and vice versa. For example when individuals attribute the actions of another to personal causes (i.e., when behaviour is believed to be internal and controllable), the observer engages in more criticism, expressions of hostility, emotional over-involvement, coercion and punitive styles of interaction towards the actor (Barrowclough, Johnston, & Tarrier, 1994; Brewin, MacCarthy, Duda, & Vaughn, 1991; White & Barrowclough, 1998). Behaviours also mediate attributions (Bromley & Emerson, 1995; Hastings, 1997;

Johnston & Patenaude, 1994). For example, observers are more likely to make internal attributions when a behaviour is unique and is observed to occur consistently (in the same way at different times and in response to different stimuli – Kelley, 1967).

The Effect of Mood on Attributions

A large body of research has also demonstrated that the *mood* of the observer can influence attributions (Conrad & Hammen, 1989; Forgas, 1998). For example, Forgas (1998) found that positive mood increased the likelihood of behaviours being attributed to dispositional factors while negative mood increased the likelihood of situational attributions. In other words, observers with a negative mood were found to be more likely to have a 'depressive realism' about the behaviour of others and were less likely to make a *fundamental attribution error* (the tendency for observers to over-estimate dispositional factors and underestimate situational factors). Thus, instead of attributing Johnny's tantrum behaviour to stable, internal characteristics e.g., "he has a lot of anger", or "he's very sensitive", people with a negative mood are more likely to attribute the behaviour to external/environmental factors e.g., "he was tired", "that other child was provoking him".

While being lenient on those they are observing, people with negative mood are very hard on themselves and tend to perpetuate their own mood by attributing failure to dispositional and stable factors. For instance, if a parent with a depressed/negative mood observed their child misbehaving, they would be more likely to attribute this to their own poor parenting abilities. Conversely, if they observed their child doing something well, they would be less likely to attribute that success to anything they themselves may have done. Forgas (1998) therefore suggests that assessing the observer's mood is an important pre-requisite to understanding attributional explanations and to identifying potential outcomes and application of parent training instruction.

The Information Contained Within Negative or Unexpected Behaviour

Parents are analytical about their child's behaviour on a daily basis. It is common for parents of young children to search for explanations for observed behaviours (Miller, 1995) particularly when the behaviours are challenging (Fösterling, 1988; Freeman, Johnston, & Barth, 1997; Gretarsson & Gelfand, 1988) or when an event occurs that is perceived as negative or has an unexpected consequence (Weiner, 1985). Through socialisation it is proposed that we acquire implicit causal schemas which we use as shortcuts to making inferences about the behaviours of others (Jones & Davies, 1965). Therefore, to understand, control and master the environment in which we find ourselves, we tend to pay attention only to odd/unusual, exceptional or important behaviours (Augustinos & Walker, 1995).

Socially acceptable or desirable behaviour ('normal' behaviour) is familiar to the observer and does not help them attribute causes or make inferences about another person. The observer has a tendency to overestimate the commonality of their beliefs, opinions and attitudes and thus if they believe they would act in a particular manner given a particular set of circumstances, they would also believe that others exhibit the same/similar positive behaviour for the same reasons. Positive or desirable behaviours therefore, do not allow the observer to draw inferences beyond those with which they are already familiar.

Negative or socially unexpected behaviours, on the other hand, provide much more information (compared with desirable or socially acceptable behaviours) and are more salient to observers precisely because they are not expected. It is not out of the ordinary to observe a three year old throwing a tantrum in the supermarket, but it is unusual and unexpected to observe a 15 year old doing the same. Similarly, it is expected that an individual receiving applause would act proud, bashful, surprised etc, but one would not expect to see such an individual display hand flapping, covering their ears, rocking or squealing in apparent terror. If the observer sees a familiar set of environmental circumstances, but the behaviour observed is unexpected, then the observer is more likely to disregard situational information and attribute the behaviour to dispositional characteristics. This

allows the observer to infer that the unexpected behaviour is due to the unique characteristics of another. Observers tend to attribute the negative actions of others to dispositional factors while attributing similar negative actions in themselves to situational factors (Jones & Nisbet, 1972). The observer is also more likely to assume that others observing the behaviour have reached similar conclusions to themselves (Ross, Greene, & House, 1977).

In summary, people pay attention to negative behaviour/s because such acts provide information which allows them to infer dispositional characteristics to the others and thus reduce their uncertainty about situations. The likelihood of inferring a negative dispositional explanation is directly proportional to the negativity or unexpectedness of the displayed behaviour.

The Salience of Challenging Behaviours Associated with ASD

Most ASD behaviours are consistent and distinctive. For example, let us consider echolalia – the tendency to repeat verbalisations verbatim. Echolalia is consistent across time and situations – the child will usually repeat all verbalisations directed at him/her and will supplement this with verbatim verbalisations gleaned from other conversations, radio/TV jingles or overheard comments etc. The result is usually non-functional, devoid of information and bizarre – most people do not expect such communication and the likelihood of others engaging in similar behaviour is remote. As the observer attempts to make sense out of an unusual situation, the likelihood of the observer attributing the behaviours to stable, internal factors is high (Fösterling, 1988). Further bizarre or unexpected behaviours would continue to support the initial attribution. Note here that as the observer attributes the unusual child behaviour to dispositional factors, they are also highly likely to view the behaviours of the *parent* of such a child as distinct from their own parenting behaviours and therefore usually ascribe negative qualities to the parent as well.

The Effects of Attributions on the 'Helping' Behaviour of Others

Responses to challenging behaviour are consistent with the observer's perception of the *function* of the behaviour (Dagnan, Trower, & Smith, 1998) and the attribution of controllability is a key mediating feature. When a behaviour is perceived to be outside an individual's control, the negative emotional response from the observer is low and 'helping' behaviour is more forthcoming. On the other hand, when behaviour is perceived to be within the individual's control, emotional responses are higher and 'helping' behaviour is less forthcoming. For example, Hastings (1997) found that when a behaviour was perceived to be a function of aggression (i.e., within the control of the individual), helpers displayed more anger, annoyance and fear. Where the behaviour was perceived to be a function of self-injury (and outside the individual's control), the reactions were more likely to be sadness, despair and disgust. Carers have also been found to be less likely to seek external opinion/support and are less likely to appropriately implement advice given by others when they believe that the behaviour is within the individual's control (Hastings & Remmington, 1994).

Parents of children without problem behaviours tend to interpret behaviour of older children as more intentional (controllable) than the behaviour of younger children and attribute negative behaviours to external or situational factors (Dix, Ruble, Grusec, & Nixon, 1986). Parents of children with difficult behaviours tend to attribute negative actions to negative internal (dispositional) and consistent personality traits (Baden & Howe, 1992; Booth, 1997; Johnston & Freeman, 1997). The temptation to believe that the persistent difficult behaviours exhibited by the child with ASD are deliberate (i.e., within the individual's control) are high especially when the skill base is superior in some areas, e.g., when a child reads at an age-advanced level but fails to follow simple instructions. Not only do such attributions increase the likelihood of increasingly punitive and negative interactions with the child, but where *observers* either implicate themselves as contributing to the behaviour or fail to believe that they can change the interaction, the likelihood of depression increases (Abramson, Seligman, & Teasdale, 1978; White & Barrowclough, 1998). Indeed, the belief that challenging behaviours are caused by factors beyond the control of the caregiver can become a

stressor in itself. The elucidation of caregiver attributions and behavioural interpretation towards the child with ASD is crucial to the development of an intervention designed to reduce family stress.

The Influence of Culture on Attributions

The above theories of attribution (along with others) have dominated the field of North American social psychology for the past 30 years and the need to make cultural distinctions is important because the propensity for people to seek explanations for societal issues and behaviour problems is contained within the predominant cultural framework. For example, White (1988) found that American adults favour dispositional explanations over situational explanations for a variety of everyday behaviours. Indian Hindu adults on the other hand, favour situational explanations over dispositional rationalisations. Western notions of the person (including the dominant New Zealand view) are essentially individualistic – emphasising the centrality and autonomy of the individual when considering their behaviour. As parents, we tend to acknowledge our own involvement in our child's positive behaviour while distancing ourselves from involvement or implication in the child's negative behaviour, instead blaming their own lack of effort (Jenson, Green, Singh, Best, & Ellis, 1998).

'Non-Westerners' notions of the person tend to be more holistic – stressing the interdependence between the individual and his/her surroundings (Miller, 1984). The attributional preferences outlined above also tend to increase with age (White, 1988) i.e., children are often less prescribed in their views compared with adults. However, this age difference is merely proposed to be a process of enculturation whereby as individuals age they tend to assume the dominant conception of the person within their own culture. The recognition of such cultural influences has important implications for the study of attributions of behaviour and parent training in New Zealand (Social Development Council, 1979). We will return to this point shortly.

Can We Change Attributions?

The process of acquiring attributions through learning and enculturation processes as outlined above would lead one to conclude that attributions are relatively resistant to change (Augustinos & Walker, 1995). There *is* evidence that changing people's points of view alters their attributional account of events. Batson and colleagues (Batson, Polycarpou, Harman-Jones, Imhoff, Mitchener, Bednar, Klein, & Highberger, 1997) found that evoking an emotional empathetic response towards an individual successfully changed attitudes and improved feelings towards an entire group. Moreover, changes were observed regardless of the gender of the actor or the perception of 'control' over the actor's actions as long as the empathetic response was evoked *prior* to the 'control' issue. Thus, there appears to be a strong indication that providing observers with an opportunity to empathise with the individual (i.e., take the perspective of the individual and imagine how the individual is affected by his/her plight) may alter the explanations attributed to challenging behaviours and thus alter consequent interactions and caregiver/child relationships. It is proposed that providing parents of children with ASD with an alternative explanation of their child's behaviour using information that is designed to elicit understanding of how ASD affects the child's world, will change parent's attributions of their child's behaviour away from a dispositional focus and moderate the perception of control.

At this point, we return to a consideration of the relationship between parent and child in terms of Assumption 3, and in particular, how this relationship is conceptualised within New Zealand culture.

A Systems View of Child Behaviour

Many authors considering an ecological approach to behaviour have proposed various models to illustrate the complexity of family behaviour relationships (e.g., Durie, 1998, 2001; Turnbull & Turnbull, 1990). The ecological model proposed by Bronfenbrenner (1979) suggests that human development and behaviour cannot be understood independently of the encompassing social context. Interactions are usually examined at a simple level; the child, his/her parents and

immediate family members. However, this family system is embedded within another that comprises the range of settings in which the family actively participates (e.g., extended family, school) and the wider community in which they live. Generally this system has a role in determining how the parents are socially supported (Public Health Commission, 1995).

This wider community context is in turn influenced by a 'societal' system (the exosystem) which consists of social structures and influences that indirectly affect the family and contribute towards societal attitudes and stereotypes (e.g., the way the child with challenging behaviour is portrayed in the media and popular magazines - Wills, 1994). The societal system determines the 'cost-benefits' of various treatment and education options, thereby limiting access to those services deemed to be 'socially desirable' (e.g., Herbert, 1995; Jacobson & Mulick, 2000). In New Zealand, as with most Western countries, there is an attempt to force social services (e.g., education, health and welfare) to operate as businesses and re-organisation or restructuring within these service agencies is common (Fulcher, 1991). Criteria for assessing families as being 'in need' of financial or respite support are becoming increasingly restrictive, contrary to the recommendations of select advisory groups (e.g., Social Advisory Council, 1987; Social Development Council, 1979) and families with children with more intensive needs in these areas are more likely to suffer the effects of these changes (e.g., Hornby, 1987).

Following the trial that resulted in a mother being convicted of the manslaughter of her autistic daughter, an independent inquiry was launched in New Zealand in 1998 to investigate the services available for people with ASD and their families. The resulting recommendations involved initiatives aimed at strengthening interagency co-ordination, identification of service gaps in the support of individuals with ASD and their families, establishing organisational leadership and professional development (Ministry of Health, 1998a, 1998b). The practical implications of these recommendations remain ethereal to many families affected by ASD.

Finally, the whole model is embedded within the **macrosystem** which refers to the attitudes, beliefs, values and ideologies inherent within a particular society.

The vast majority of parent training literature has been dominated by the values, beliefs and practices of the European-American culture and translated into 'norms' for parenting behaviour and optimal child development (Garcia Coll, Meyer, & Brillon, 1995; Stewart & Bennett, 1991). As a result, other ethnic parenting practices have often been viewed as deficient or defective – perpetuating a *culture-specific* 'parent-blame' myth. Cultural values and practices are not necessarily barriers to parent training but failure to understand them can hinder parent training effectiveness at best and at worse, can be seen as a method of getting children to conform with mainstream expectations and behaviours (Durand, 1990) and thereby reinforcing (further) the dominant cultural view of the parent-child relationship and interaction.

In New Zealand, society has defined the current parent-training philosophy. For example, two dominant and well publicised parenting programmes – Parent Effectiveness Training (PET – Gordon, 1975) and Systematic Training for Effective Parenting (STEP - Dinkmeyer & McKay, 1976) - are based on the respective beliefs that the child has an inherent desire to do what is 'right' (note the social construction of 'right' behaviour) and that the child seeks to belong to a social unit (which is proposed to be their primary purpose in life). Besides the strong cultural determination of 'correct' behaviour and life goals evident within these two parent-training philosophies, both fail to benefit families with children with ASD who by nature of their condition, have failed to develop social awareness. We shall return to this point later. At this stage, it is pertinent and imperative to consider the cultural climate as it affects the family in New Zealand and in particular, the cultural influences on the family with a child with a disability or severe behaviour.

New Zealand Culture, The 'Family' and Challenging Behaviour

Ko tō ringa ki ngā rakau a te Pākeha hei oranga mō tō tinana
Seek the skills of the Pakeha for your physical well-being

Ko tō ngākau ki ngā taonga a ō tīpuna hei tikitiki mō tō māhunga
Cherish the treasures of your ancestors as a plume for your brow
Sir Apirana Ngata (1949)

The current diversity of family life evident within New Zealand derives from two major traditions – Polynesian and northwest European. The Polynesian tradition consists of the Māori (characterised by a history of extensive kinship networks and hapu 'governance') and island Polynesian (strongly resembling the Māori in form and function but like the Pākeha, with a social and cultural focus usually external to New Zealand). The northwest European tradition is comprised of the Pākeha (who introduced the influences of Christianity, individual land ownership, secularisation, individuation, mechanisation, industry, wage-labour and urban centralisation) and the continuing influx of new generations of migrants.

Despite the weakening of hapu and whanau organisations and the undermining of the social and cultural basis of Māori society, Māori family life continues to be whanau based by household composition and family interaction patterns compared with the Pākeha family. The process of tino rangitiratanga (self-determination) is sought through pursuing aims of identity, shelter, leadership, and collectiveness (Tawhiwhirangi, 1991) and through key values of reo (language), whanaungatanga (relationship/relatedness), wairua (spirit) and whenua (land). The implications of the cultural differences between the two dominant people groups in New Zealand in terms of parent training are both basic (e.g., parents are not necessarily the sole, or even the key, family decision-makers in the Māori community – Cairns, 1991) and profound, calling into question the entire service delivery and practice model for difficult child behaviours (e.g., Evans & Paewai, 1999).

Forehand and Kotchick (1996), in an excellent paper on cultural diversity, challenge the belief that parent-training can be effective if it is devoid of cultural context. Parenting behaviour and guiding values are shaped by intercultural and intracultural practices, tensions and the dynamics of cultural discrimination in the wider society (e.g., Beatson, 2000). Parenting in impoverished socioeconomic conditions and mistrust of the majority culture have been cited by some (e.g., Dodge, Petit & Bates, 1994) as contributing towards emotional unavailability and harsh disciplinary practices. These parenting practices, in turn, are viewed as necessary for the development of emotional independence and physical survival in

children. Of course, it can also be argued that impoverished conditions leave few emotional resources to manage child behaviour.

Behaviours considered necessary for success are also determined by culture. For example, the socialisation of compliant behaviour is proposed to be a characteristic of groups that view the sub-ordination of their individual members to be a crucial feature of their workplace survival. In comparison, in economically stable groups, the emphasis is on training individuals to be independent and assertive (Forehand & Kotchick, 1996; Harkness & Super, 1996; Ogbu, 1985). Culture also has an influence in determining beliefs about disability, the value of the child and appropriate parent-child interactions.

It is noted that Māori are under-represented in the ASD statistics available in New Zealand (personal communication with Autism Inc., New Zealand, 2002, revealed that less than one percent of members describe themselves as New Zealand Māori). It is the opinion of this author that these figures result from a fundamental difference in how the behaviours inherent within the ASD condition are viewed between the two dominant traditions in this country. This view supports that noted by others (e.g., Bevan-Brown, 1994; Tihi & Gerzon, 1994). In Māori culture, there is actually no equivalent term for 'disabled' (Bevan-Brown, 1994; Wilkie, 2000). Individuals with physical or intellectual disabilities are generally accepted and valued as integral community members. At times, they are even treated as tāonga (treasure) and revered.

The values, quality and types of behaviours we encourage in our children are culturally determined. Behaviours exhibited by Māori children are not necessarily viewed in terms of 'challenging' or 'unmanageable' because to do so requires a view of the child in isolation. There is also reluctance among Māori to fit personal development into a pre-determined time frame. Rather, learning and development are valued as ongoing and lifelong processes. In contrast, in Pākeha culture, an individual focus and emphasis on authority and discipline means that individuals with a disability are often required to conform to acceptable societal standards or else become marginalised. Children who exhibit socially unacceptable behaviours are expected to conform to societal 'norms' of behaviour and development which

require children to function within particular behavioural boundaries. Failure to do so means the behaviour is the fault of the individual and/or the parent/person responsible for behaviour management. Attempting to explain, predict or change parental behaviour (as targeted within parenting programs), is meaningless and ineffective without reference to cultural beliefs (Harkness & Super, 1995).

Census figures continue to depict continuing change in the ecology of the New Zealand 'family'. Older parents, fewer siblings, childcare experiences outside the home, parent/s working, increasing separation, divorce and 'blended' family arrangements continue to challenge parent training research and application of parent training techniques in a New Zealand context (Hopa, 1991; Masoe, 1991). While most New Zealanders share common economic concerns, the need to nurture extended family relationship values (including language and tradition) are more culture-specific. Current migrants to New Zealand are faced with a continuing ambiguity between current migration laws and regulations emphasising a nuclear family model and their own family traditions. This is far from a minor issue given that Māori, Pacific and Asian populations have grown by up to 138% in the past decade, while New Zealand European population growth over the same period has been just 3% (Statistics New Zealand, 2001). At this growth rate, population projections indicate that people of Polynesian tradition and Asian migrants will make up the majority of the New Zealand population by 2040.

In conclusion, the assumptions, attributions and practice of parent-training have arisen within a specific cultural context. Elucidation of this limitation does not negate the benefits documented in the parent-training literature, rather, it allows therapists to carefully consider the premises and implications of parent-training philosophy and adjust practice accordingly. Changes which affect children and families cannot be considered in isolation from ecological and cultural variables. As Gabrielle Maxwell so succinctly concluded; "...the differences (in culture) are real and to acknowledge them implies more than just understanding, it implies also a readiness to share power and resources..." (Maxwell, 1991, p. 160).

This research project utilises a parent-training approach for those parents/caregivers (with children with ASD) who identify the behaviours their child exhibits as challenging and impinging on family function. An emphasis on the use of parents or caregivers to identify valid target behaviours and determine appropriate outcome goals is proposed to be culturally sensitive. The major aim is for parents and caregivers to participate in a process that attempts to share/develop skills and knowledge in a manner that is deemed to be appropriate for the individual family in order to facilitate successful parent-child relationships and enhance family functioning.

The Practice of Parent Training and Parental Involvement

Parent involvement in co-operative training models still varies enormously. At one end of the range, the parent carries out strictly defined instructions given by the therapist with little or no systematic training involved. At the opposite end of the continuum, the parent acts as therapist in observing, analysing, planning programs, implementing and evaluating interventions. Partnership in intervention requires equal access to information and resources (Webster-Stratton & Herbert, 1993). To date, perhaps because of research requirements, most attempts to include parents in intervention have fallen within the 'directive' or 'co-therapist' end of the range where at best, parents are taught some skills but are largely dependent upon the therapist facilitating child behaviour change.

Most programmes and professionals currently available in the field of ASD adhere to a basic therapist-child intervention model. Notable exceptions are the TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) model (Campbell & Schopler, 1989; Marcus & Schopler, 1989; Mesibov, 1995, 1996; Schopler, 1994), National Autistic Society (NAS) Earlybird programme (e.g., Shields, 1999) and Howlin and Rutter's (1987) treatment approach. However, many parents look to professionals, therapists or trainers in established programmes, believing that others have the skills and knowledge necessary to maximise learning opportunities and accentuate their child's development. Success appears to be dependent on operator and professional oversight. Where parent-training is included, it is often as an adjunct

to the dominant model and parent interaction is limited. This practice leaves the parent vulnerable to the vagaries of the parent-professional relationship and leaves families devoid of control and input. A level of 'hollowness' can develop when the parent/caregiver role and input is perceived to be unvalued. Tension and ambiguity can arise over the construct of parent/professional 'expertise' (Avdi, Griffin, & Brough, 2000).

In interventions involving a child, the parent's lifelong hopes and needs drive the desire to acquire skills and knowledge to assist the child's development. Parents often question, 'what drives the involvement of the professional?' (Wills, 1994). Attempts to align themselves as equal partners in their child's intervention programme can leave some parents/caregivers ostracised and labelled as radical (Brown, 1994). Parents and caregivers generally believe they are expected to defer to the professional opinion and direction and should show gratitude for the professionals' interest and input. Many subsequently leave the relationship feeling that professional decisions did not empower the family or result in gains that were in the family's best interests.

We live in a society that is deficient in accessible and available professionals, endorses personal independence and resourcefulness and is unwilling to tolerate aberrant behaviours. Within the family with a child with challenging behaviours, the simple requirement for direct and practical alleviation of daily difficulties is often outside current therapy approaches. Where professionals are available and accessible, they have the ability to enter a family system, change contingencies (or teach parents to change contingencies) and leave. Intervention is often limited to the specific and current problems at hand and is not aimed at teaching the parent general principles and strategies for promoting future independence (Koegel, Schreibman, Johnson, O'Neill, & Dunlap, 1984; McMahon, Forehand, & Griest, 1981). Principles of behaviour are also required to produce long-term and durable change (McMahon & Forehand, 1984).

The parent and his/her relationship with the child is an implicit part of family functioning. This relationship is dynamic, intimate and emotive. Rather than teach parents to become 'aides' to the professional or train them in a prescriptive series

of behaviour management strategies, this study aims to utilise the role of parent-participants as *parents* first and *'therapists'* secondly. This aim is based on a twofold premise. Firstly, that the relationship dynamics between parent and child are unique and largely inaccessible to the therapist and, secondly, that therapist intervention is temporary whereas the parent-child relationship both by itself and within the wider family context is enduring and will affect family functioning over time.

In this study, 'parent training' refers to the method of therapist-parent interaction whereby parent skills and knowledge are augmented in order to a) enhance existing parent-child relationships and b) enable parents to reduce the negative effects of challenging behaviour on family functioning. The ultimate goal of this approach is to improve parent-child relationships in order to strengthen family functioning and alleviate family stress. With these goals in mind, the remainder of this introductory section examines the proposed *content* of the parent-training approach.

Behaviour Analysis

It is recognised that behaviour analysis with its variants (e.g., applied behaviour analysis - ABA, functional analysis of behaviour - FAB) is the best empirically evaluated treatment available for reducing problem behaviour (e.g., Kerr, 1999) and building repertoires of complex and functional skills in individuals with ASD (Campbell & Schopler, 1989; Matson, Benavidez, Compton, Paclawskyj, & Baglio, 1996; Rosenwasser & Axelrod, 2001; Smith, 1996). Behaviour analysis has a solid theoretical basis. It lends itself to empirical validation and is strong in individualising treatments. Behaviour analysts have an ethical duty to provide recipients of behavioural intervention with effective programmes and competent service. Recipients have the right to expect that training programmes will provide them with culturally appropriate skills that will increase their adaptive functioning and the right to access interventions that are subject to scientific validation and ongoing evaluation (Green & Perry, 1999; Schopler, 1996; Van Houten, Axelrod, Bailey, Favell, Foxx, Iwata, & Lovaas, 1988).

Behaviour analysis is a basic three-component process that seeks to describe or operationalise a behaviour in sufficient detail so as to allow reliable observation and measurement (e.g., Campbell, Schopler, Cueva, & Hallin, 1996; Cataldo, Slifer, & Summers, 1994). An attempt is made to clarify those contingencies that cause or maintain target behaviour by deliberate manipulation of the variables that precede behaviour (antecedents) or reliably follow it (consequences). By objectively measuring behaviour while manipulating antecedents or consequences, it is possible to demonstrate the effect of these manipulations on the frequency, duration or intensity of behaviour. Behaviour analysis is often misconstrued as consisting of only simple antecedent-behaviour-consequence contingencies. Contrary to popular opinion, behaviour analysts also have substantial interest in language, cognition and complex challenging behaviours. For the purpose of this research, the arguments concerning the parameters of behaviour analysis are left to others (e.g., see Hayes, 1989, Skinner, 1957).

The application of behaviour analysis does not depend on successful elucidation of cause or identification of the neuro/psycho/biological site of dysfunction. Instead, behaviour analysts consider the presentation of the behaviours manifest in conditions such as ASD as a series of discrete skill domains that occur in excess or deficit. Behavioural *intervention* is based on the premise that identification and manipulation of the current maintaining variables is all that is required to change behaviour (Fish, 1995). This approach is distinctly advantageous given the proliferation of theories and controversy within the field of ASD. It also provides a hopeful and empowering alternative to the view that ASD is a lifelong condition which is not amenable to effective treatment (Kerr, 1999).

Applied Behaviour Analysis

Applied behaviour analysis (ABA) was first described by Baer, Wolf, and Risley in 1968. To the basic behaviour analysis approach, concepts of application, technology, generalisation and effectiveness were added. The most significant push in this field was to constrain research to those behaviours deemed to be of social importance. The *application* of behaviour analysis meant that the study of these behaviours occurred within their natural setting as opposed to being

contrived in an experimental environment. *Technology* referred to the identification and description of techniques used in intervention in sufficient detail so that precise replication could be attempted. Techniques were also required to be derived from basic principles and related conceptually to recognised and clearly defined systems. Changes in behaviour were expected to be stable and durable over time, setting and behaviour (i.e., *generalisable*) and perhaps most importantly, changes in behaviour were expected to be *effective*, i.e., large enough to be deemed socially valid (rather than statistically significant) and of value to both those who exhibit the behaviour and those who deal directly with the consequences of behaviour (Schwartz & Baer, 1991).

Early ABA Work in the Field of ASD

Behaviour analysis interventions for children with ASD began in the 1960s with the work of Ivar Lovaas and colleagues in the United States. Their widely cited study (Lovaas, 1987) demonstrated that with appropriate intervention, children could make intellectual and social gains beyond previous expectations. 'Appropriate' intervention was costly and intensive – one to one therapist-child training at least 40 hours per week and an expectation that the parent/s would continue intensive intervention beyond these times. However, differences between experimental and two control groups were significant with 47% of participants (n=19) achieving IQs greater than 100 compared with 2% of control participants achieving the same.

Lovaas's original programme has been replicated in various guises around the world in the field of ASD. It is currently available in New Zealand through private providers based in Australia – Intervention Services for Autism and Developmental Delay (ISADD) among others. In her book 'Let me hear your voice', Catherine Maurice (1993) outlines an adaptation of an American-based programme that she credits 'freed' her two children from autism. Lovaas's early work paved the way forward for children with ASD and their families and the field of applied behaviour analysis in treating autism. In particular, the primary focus on language training showed that 'inclusion' of children with ASD into mainstream education was an achievable goal. There are a number of extensively

documented cases of intensive ABA enhancing the intellectual functioning and verbal ability of children with autism (e.g., Eikeseth, Smith, Jahr, & Eldevik, 2002; Keenan, Kerr, & Dillenburger, 2000). Such programmes have also been credited with moving very young children with ASD into the normal range of functioning (e.g., Green, Brennan, & Fein, 2002). However, cautions remain.

Children with autism vary markedly in response to intensive behaviour treatment (Lovaas & Smith, 1989). Almost half of Lovaas's experimental group showed impressive gains, the other half had variable results. Other programmes based on intensive 'ABA' techniques have repeatedly resulted in a group of individuals who do not appear to benefit greatly from intervention. Some participants show extremely slow progress, others fail to progress at all. Many theories abound as to the reasons behind these discrepant outcomes (e.g., Sundberg & Michael, 2001) and some researchers propose that the difficulties lie in a failure to adhere to the clear tenets underlying basic ABA principles as originally espoused by Skinner and others (e.g., Baer, Wolf, & Risley, 1968).

'ABA' is currently heard as a popular lay term among treatment providers and within the ASD community to signify a particular type of intervention. The general consensus is that this treatment type is desirable and even 'essential' to the progress of the child's development. In practice, the actual implementation of ABA techniques is often variable and in some cases – questionable. The provision of such treatment is driven by market demand and standards of administration have the potential to be compromised as a result. Moreover, the cost of such an intensive intervention to families in New Zealand is in the vicinity of tens of thousands of dollars per annum.

ABA and the Impact on the Family with a Child with ASD

'ABA' as currently offered to families with a child with an ASD is believed to consist of an intensive one-to-one training programme comprising of interactions between a 'trainer' and the child. It is usually recommended that training occur for up to 40 hours per week and over a long period of time (months to years). The administration of such a programme hinges on the commitment of the family to an

intensive and long-term programme. The stressors that accompany the practical aspects of implementing such a programme are considerable not only in terms of *objective* strains (e.g., time and financial commitment), but also in terms of *subjective* stressors (Hastings & Johnson, 2001). The family place their hopes, expectations and vulnerability in the skills, professionalism and competency of their individual trainer or trainers. Some parts of the programme may be administered by the caregivers themselves, often the mother, who must act in multiple roles – trainer, educator, reinforcing agent, parent. Families must also be prepared to see their young son/daughter being trained in a highly regimented and prescriptive fashion by people outside the family unit. Catherine Maurice (1993) gives candid insight into the conflicting emotions she experienced as she observed the trainer administering such a programme with first her daughter and later, her second son.

There is considerable pressure on families to act in the early year of development while the child's brain is relatively 'plastic' and more susceptible to change (Niemann, 1996). The emphasis, pressure and importance attached to early, intensive behavioural intervention often occurs at a time when the family is still trying to come to grips with an unfamiliar and lifelong diagnosis. It plays directly upon the fears of the family that they must maximise learning potentials during a small 'window of opportunity' or risk making choices that will effectively limit their child's development. As already stated, research suggests that the majority of (e.g., high-functioning) individuals with ASD will not be diagnosed until after they start school, thereby indicating that the critical 'window of opportunity' may already be lost. This can be a devastating realisation for families coping with the implications of a diagnosis of ASD and further contribute to parental guilt and loss of hope.

Pelios and Lund (2001) conclude their overview of the application of ABA to the field of autism with the statement that "it [ABA] constitutes the only reliable form of intervention to improve the lives of children with autism *and their families*" (p. 694, italics added). There is little doubt of the efficacy of ABA in producing desirable outcomes for *children* (and child behaviour – e.g., Maurice, Mannion, Letso, & Perry, 2001; Weiss, 1999). The advantages for the family however, are

less direct. ABA as it is usually practised has a strong child-focus. Family functioning appears to benefit because interventions aimed at the child are assumed to improve child functioning and therefore reduce family strain. This approach continues to fail to address the subjective strain associated with the parent/caregiver's perceived inability to effect desired changes in their own family. This current study seeks to decrease family strain by equipping caregivers and parents with the behaviour analysis skills required to effectively and positively manage and change child behaviour themselves. It is proposed that empowering parents/caregivers to make changes in child behaviour will alleviate subjective strain and increase family functioning.

Applied Behaviour Analysis as an Approach to Challenging Behaviours Associated with ASD

It has already been ascertained that behaviour analysis leads to effective and valid intervention. However, it is also technically cumbersome and difficult to apply without considerable training or reliance on trained personnel. One conceptualisation of challenging behaviour that has led to effective and successful interventions for developmental disorders is a functional analysis approach (e.g., Hemsley, Howlin, Berger, Hersov, Holbrook, Rutter, & Yule, 1978). Rather than promoting an intensive intervention based simply on contingency management, functional analysis of behaviour focuses on the *purpose* or *function* underlying a particular behaviour (Kazdin, 1994). Many behaviours have similar topography or appearance, but the function underlying the behaviour may vary. For example, tantrum behaviours could be motivated by attempts to obtain a tangible object, escape from an aversive situation or to obtain social attention etc. Using a functional approach, the key to successful intervention lies in the ability to match the functional outcome to another more desirable or socially appropriate behaviour (i.e., functional replacement). For example, a child may be taught to use a pictorial card to signal a need for 'time out' from a demanding task rather than hitting his/her teacher aide or classmates, thereby allowing a new behaviour to fulfil the same function as the target behaviour but in a more socially acceptable manner.

History

Functional analysis techniques were first described and emphasised in the late 1960's (e.g., Kanfer & Saslow, 1969; Wolpe, 1969). However, a growing focus on consequence-based behaviour modification practices (e.g., Walker & Shea, 1995) led to a decline in the use of functional approaches. Groden (1999) proposed that this decline may have stemmed from misconceptions of Skinner's (1938, 1953) early behavioural work which led to the mistaken perception that consequence-based procedures were sufficient for the control of behaviour. Following the failure of various treatment interventions, functional analysis was examined again in the late 1970's but consequence analysis dominated behaviour therapy for the next decade. In the late eighties, aversive punishment techniques were still considered to be the most successful intervention available (Matson & Taras, 1989).

Over the past decade, two research trends have led to an upsurge in the interest and study of functional analysis. One of these trends was the structured use of functional assessment methodology designed to increase treatment effectiveness (Iwata, Dorsey, Slifer, Bauman, & Richman, 1994; Kazdin, 1994). The other was an increasing voice for the rights and welfare of individuals to receive humane (non-aversive and less intrusive) treatment interventions (Evans & Meyer, 1985; Luiselli, 1990). However, despite these new directions, behaviour modification programmes in the field of education in New Zealand continue to be dominated by consequence-focused directives, at the expense of antecedents.

Reinforcement Classes and Functional Replacement

The functional analysis approach begins with careful assessment and analysis of antecedent events and consequence responses with the aim of identifying the reinforcement classes underlying a particular behaviour. Both descriptive and experimental assessments are utilised to formulate hypotheses about the functions underlying target behaviour/s (e.g., Sasso, Reimers, Cooper, Wacker, Berg, Steege, Kelly, & Allaire, 1992). Following careful assessment, the ultimate aim behind functional analysis is to replace the problem behaviour with an alternative

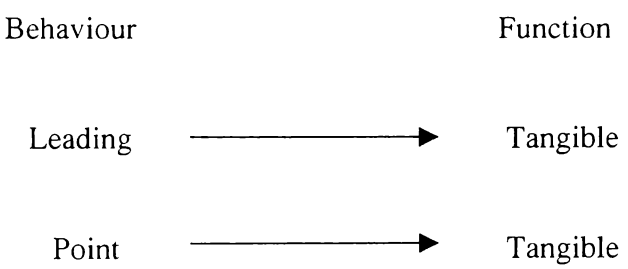
behaviour which can perform an equivalent function for the individual. In effect, the individual is able to access the same reinforcement class albeit in a more socially appropriate manner. The critical examination of functional relationships determines the success of the proposed intervention (Horner, Day, & Day, 1997; Richman, Wacker, Asmus, & Casey, 1998).

Functional analysis literature suggests that problem behaviours are maintained by two broad reinforcement classes:

1. Escape/avoidance behaviour which is negatively reinforced and
2. Acquisition/attention behaviour which is positively reinforced.

A third category, automatic reinforcement (e.g., sensory feedback associated with self-injurious behaviours), has been the subject of many studies (e.g., Berkson & Tupa, 2000; Kuhn, DeLeon, Fisher, & Wilke, 1999) and its inclusion as a reinforcement class shows an enlightened move away from a narrow focus on socially motivated behaviours to consider the implications of behaviour/s that do not appear to be socially maintained. This point is important when considering the behaviours of individuals with an ASD and will be referred to again later in this section.

When various behaviours are identified as being maintained by the same reinforcement class, they are said to be functionally equivalent. For example, autistic leading (taking an adult by the hand to a preferred toy/activity) and pointing both serve a tangible function. Both behaviours communicate a message to the observer of "I want that". The goal or function of the two behaviours is to obtain something and both behaviours are said to be functionally equivalent. Once the function of a particular behaviour is identified, it may be replaced by a more appropriate and desirable behaviour from the same reinforcement class (Carr, 1985). In this example, leading behaviour could be replaced with pointing behaviour.



Studies have found that behaviour problems and communication difficulties are often directly related in both 'typical' children and those with developmental disabilities (Carr & Durand, 1985; Carr, Levin, McConnachie, Carlson, Kemp, & Smith, 1994; Sigafoos & Meikle, 1996; Talkington, Hall, & Altman, 1971). This has led to the practice of replacing problem behaviour with behaviours that have a communicative function e.g., verbalisation, signing and use of exchange card systems (Durand, 1990).

Traditional functional methodology as outlined by Iwata and colleagues (1994) utilised a systematic analysis of negative, positive and automatic reinforcement conditions designed to evoke target behaviour. Once a function was proposed, an experiment was performed whereby the function and alternative functions were tested. This experiment was undertaken to increase the certainty that the proposed function was indeed the best option. However, as in all fields concerned with human behaviour, the function of some target behaviours is not easily determined and initial functional analysis data may be inconclusive. Various researchers have stressed the importance of a thorough investigation of establishing operations and antecedent or maintaining contingencies (e.g., Horner, Day, & Day, 1997; Michael, 1993). Multiple antecedent conditions may combine to produce a behaviour where each condition alone does not appear correlated to the occurrence of the target behaviour. For example, Fisher and colleagues (Fisher, Adelinis, Thompson, Worsdell, & Zarcone, 1998) found that a preferred activity may act as an establishing operation and increase the aversiveness of a terminating request. Thus disruptive behaviour may be *positively reinforced* by applying a terminating demand because a demand may increase the rate of negative behaviour when applied to a preferred activity. This is in contrast to the expectation that negative behaviour will be reduced (negatively punished) by terminating the activity.

Functional analysis techniques work on the assumption that teaching or strengthening functionally equivalent responses will result in the simultaneous weakening of the target/problem behaviour. Researchers have found that this inverse relationship occurs without any direct contingencies being placed on the

target behaviour itself (Carr, 1988; Tucker, Sigafoos, & Bushell, 1998). In behavioural terms, this effect is bought about by eliminating the functional relationship between the target behaviour and the reinforcement class by eliminating the establishing operation for the behaviour (the individual no longer needs to engage in the problem behaviour), or extinction (the behaviour no longer results in the expected outcome). The efficiency and success of the new behaviour in replacing the old can be conceptualised along dimensions of reinforcement consistency, delay and density (Carr, 1988; Tucker et al., 1998).

The Benefits of a Functional Analysis Approach

The implications of a functional analysis approach are significant. Traditionally, problem behaviours have been dealt with by means of aversive consequences (Walker & Shea, 1995). Often target behaviours had to be 'eliminated' before educational learning or placement took place. Eliminating problem behaviour without providing alternative responses may lead to learned helplessness and leave the individual with a clear understanding of the response to undesirable behaviour but in doubt as to meaningful alternative behaviours (Carr, 1994; Marcus & Vollmer, 1996). A functional approach supports a focus on skill building and teaching new behaviour in any given setting. The current problem behaviour also serves an important guide for the level of functioning and skills already within the individual's repertoire. Traditional behaviour analysis techniques often focus on the individual's internal state of motivation in determining the potential effectiveness of intervention. However, the examination of the function underlying problem behaviour allows us to consider that the motivation for the behaviour already exists – what the child needs is a socially appropriate form of behaviour to serve the function they have already accessed.

Functional analysis is an important approach to treating problem behaviour and has clear advantages over more traditional ABA techniques (Durand, 1990). It focuses on skill building and promotes positive techniques to identify and build replacement behaviours. It does not require intensive technical expertise. Functional analysis of behaviour however has limitations – particularly when functional methodology is applied in a rigid or prescriptive manner.

As outlined in the previous section, functional analysis is a form of behaviour analysis and as such there is a potential danger of considering the child's behaviour in isolation and failing to take into account the family context, child-rearing patterns and available support systems. While it is acknowledged that these factors may not be deemed vital to producing positive behaviour change, they *are* vital in ensuring long-term maintenance of gains and durable relief of family stress. Studies in controlled research environments have helped advance understanding of functional concepts and mechanisms, however, the practice of implementation of such techniques in an applied field varies in feasibility.

A functional analysis depends on showing that a given target behaviour is controlled by specific events (Kazdin, 1994). In the interests of application, a full functional *analysis* including controlled manipulation of the functional variables (e.g., Roscoe, Iwata & Goh, 1998) was not implemented in this study, but functional analysis *assessment* techniques and procedures remained pertinent and were utilised (e.g., Sasso et al., 1992). Accordingly, throughout the remainder of this thesis, the programme component and techniques derived from functional analysis literature will be referred to as "applied behaviour analysis" keeping in mind that this term includes a functional assessment emphasis. The *concepts* of functional analysis are utilised to enhance participant understanding and explanation of challenging behaviour. This focus serves as a departure from traditional behaviour analysis techniques in that it promotes an alternative way of looking at the environment and context within which the behaviour occurs and attempts to identify the function underlying target behaviour/s.

Let us return to the example of Joey, as outlined earlier.

Joey (aged 4 years and diagnosed with ASD) has a pattern of escalating violent behaviour towards other children in his preschool setting. Joey is an only child and has shown no animosity towards other children in his home environment. Adults in the preschool believe that Joey's behaviour is the result of lax expectations and ill-defined limits at home. A 'time out' procedure fails to alter

Joey's behaviour and heightens both the perplexity and tension of the preschool staff and Joey's mum.

Upon further analysis, the behaviour was outlined as follows;

Regularly upon arriving at his preschool, Joey hits several children in the face with an open palm and with arm extended. It is not a 'hard' slap but is deliberate and other children are understandably surprised and upset. The response to this behaviour varies in terms of participants but basically consists of adults comforting the injured child, berating Joey - "No" and separation of Joey from the other children for a few minutes (time out). During the remainder of the session, Joey does not seek out adult attention, he plays alongside other children and no one child or set of children are the target of ongoing negative interactions. Joey shows little reaction to the hitting situation except occasionally a slight smile and/or widened eyes. If prevented from hitting by physically holding his arms by his sides, Joey simply completes the behaviour as soon as he is released.

The above scenario and what followed is based on a real case. While the target behaviour is continuing, it is being reinforced. Using an applied behaviour analysis approach, one could hypothesise a positively reinforced function e.g., adult *attention* (even negative), getting to go to the 'time out' area (perhaps in order to *attain* something) or a negatively reinforced function e.g., avoidance of greeting behaviour, removal of other children when placed in time out, or avoidance/removal from the initial disruption caused on arrival at the centre and getting settled for the day *(escape)*. A *sensory* function could possibly exist, e.g., Joey may like the tactile sensation of hitting.

Attempts to experimentally analyse the situation produced inconclusive results. Time-out and negative attention in the form of beration did not decrease the behaviour. In fact, the frequency of the behaviour had been observed to be increasing. A consideration of the possible functions underlying the behaviour may result in removal of adult attention (e.g., ignoring), teaching Joey to request attention, changing the 'time-out' area, keeping other children away from Joey or setting up a system for settling. All of these functions were tested and all proved

unsuccessful in eliminating the hitting behaviour. It is common at this point that the focus turns to the family and the child is asked to leave the early childhood setting.

As already outlined, acceptable or unacceptable behaviours are socially and culturally determined. Moreover, the consequences applied to behaviour are also socially and culturally determined. Applied behaviour analysis, like most behaviour based treatments, is based on a shared understanding of social behavioural norms and parameters. For example, we would expect that removing a child from their social group or peers would be punishing, just as we would expect that giving a child a sweet or toy would be reinforcing. While a careful, thorough and thoughtful applied behaviour analysis could hit upon the correct underlying function, some behaviours associated with the condition of ASD continue to challenge the therapist because they do not readily conform to behavioural modification techniques or typical applied behaviour analysis approaches. This is proposed to be because while the topography of the behaviours associated with the condition of ASD and non-ASD behaviours are similar, the former are inherently different and may arise from a completely different basis which is not socially determined. We shall return to this idea shortly with a discourse on a theory that is proposed to underlie the characteristic features of ASD. Before doing so however, we return to Joey.

The behaviour exhibited by Joey *was* being positively reinforced and *was* performing a communicative function; that being 'hello' or greeting. Joey's lack of social understanding combined with the knowledge that greeting behaviour crudely consisted of an interaction between two individuals had led to the development of a behaviour that allowed him to participate in an 'approach' behaviour with others. Teaching Joey simple greeting behaviour and walking him through it upon entering the preschool setting saw the disappearance of hitting behaviour and a lot of happier children and adults! This was not the end of behavioural issues for Joey but was the successful resolution of this particular behaviour.

Interestingly, a very similar behaviour was observed in another child with an ASD, Blyth. In this situation, the function of the behaviour was sensory – however, not tactile as expected. Rather, Blyth loved the way he could make a person's face change to sad/crying complete with water coming out of their eyes. His hitting behaviour was being visually reinforced. Understandably, the topography of his negative behaviour complete with apparent glee at the 'injured child's' distress caused a great deal of concern and negativity among adults in the situation and eventually Blyth was removed from social settings due to a lack of ability to control his behaviour. In this case, understanding of some of the typical features of ASD could have led to the development of an intervention aimed at teaching Blyth to identify and understand simple emotions (e.g., allowing him to observe emotions both in himself and others or teaching him appropriate social responses). Facilitation of his own social development and understanding may have mitigated the negative reactions from others.

Too often, the parents of such children (and the children themselves) bear the brunt and social antagonism from the problem behaviours of their child/ren. Families withdraw socially and parents are held 'responsible' for an apparent lack of 'child management skills'. The key to successful remediation in these cases is found in information specific to the condition of ASD. Until fairly recently, ASD behaviours were simply viewed in terms of excesses or deficits and contingency management was the intervention of choice (e.g., Charlop & Trasowech, 1991; Dempsey & Foreman, 2001; Sanders & Dadds, 1993; Schreibman & Koegel, 1981). We now turn to an area which while relatively new, lends itself to a new view and understanding of the behaviours associated with the condition of ASD.

Theory of Mind as an Approach to Challenging Behaviours Associated with ASD

> These children appear to "come into the world with an innate disability to form the usual, biologically provided affective contact with people" (Kanner, 1947, p. 250).

As there are many divergent proposed causal mechanisms in the field of ASD, so too are there many theories about the link between the causal agent and the behavioural manifestations of ASD. The major debate centres on whether autism

is a primary neurobiological disorder that affects social and affective development (alluding to Kanner's original observation above) or whether it is the social and affective manifestations which are in turn secondary to some other perceptual or cognitive dysfunction (eg., Dawson & Lewy, 1989 – central modulation theory). This debate is well documented in other papers (e.g., Pelios & Lund, 2001) and is not the focus of this research; however it sets the background against which a promising 'primary' theory is proposed – Theory of Mind.

Theory of Mind (ToM), a term first used by Premack and Woodruff (1978) with respect to work being undertaken with chimpanzees, refers to our innate ability to explain, predict and interpret behaviour by attributing mental states (e.g., belief, intention, thought and desire) to self and others. From a very young age, normally developing children are aware that other people hold information in their heads. They are aware that this information can be different from the information they hold in their own head. From the age of two years, typically developing children can correctly manipulate objects with reference to the view and perspective of someone else. They develop understanding of the principle that 'seeing-leads-to-knowing' and they understand that knowledge, perspective and the information in other people's heads can lead to particular behaviours and actions. They know that pretence is different from reality and can improvise and use imagination to create new functions for different objects or situations. From the ability to discriminate basic facial expressions as infants, children develop an understanding of how situations affect emotion and how both desires and beliefs affect how someone will feel (Happé & Frith, 1999; O'Connell, 1998). Individuals with ASD are believed to have a deficient or impaired 'theory of mind'.

Consider a characteristic 'ASD' behaviour – lack of eye gaze and greeting. Most children and infants would know that a smile and/or verbal "hello" directed at another person would elicit a similar response from that person. We have a shared understanding of the social expectations around simple greetings. We know that a smile most commonly represents approach behaviour and attribute the person who initiated this behaviour as being friendly and welcoming. In other words, we would expect that we could safely approach this person and engage in further positive interaction with them. Consider the situation that occurs when we initiate

such behaviour and the person it is directed to *does not* supply the expected response. Our immediate reaction is usually 'did they see/hear me?' or negative 'how rude/aloof' etc. Our behaviours at this point usually reinforce our belief e.g., try to gain the person's attention again or move away/act in such a manner so as to deliberately avoid or rebuff further social interactions.

Now consider this scenario from the understanding (or more accurately – *lack* of understanding) of a child with ASD, whom we shall call Billy. A smile directed towards Billy (and observed) elicits no response. Billy initially stares at the child with no discernible facial expression, starts to hum in a monotonous manner and eventually moves off and starts to play by himself. Billy is not being deliberately rude – he does not know that the child smiling at him is 'communicating' a welcome. He does not share the understanding that a smile signals an approach-behaviour and is completely unaware that the smiling child has in mind to initiate a further interaction with him. He does not attribute any mental states or general traits to the first child because the smile is meaningless to him – it is simply a mechanical movement of the face. Similarly, he fails to watch or check other peoples' faces because he does not understand that the face (and in particular the eyes) can communicate intent, desire, emotions, approval or disproval. He is not aware of the social use of eye gaze to determine proximity, to communicate feeling, to facilitate a sharing of information or to regulate interaction.

We understand that people are different from objects. People have volition, emotions, beliefs, fears and numerous other cognitive states that add purpose and understanding to their vocalisations, movements and behaviours. Individuals with ASD appear to lack this ability to decipher the difference and often treat other people and objects alike:

> People moved in relation to me and talked to me, but, as far as I can remember, I did not reciprocate. I do not mean that I did not move, but that my movements concerned me and not others. I did not mean to be as uncooperative as I was, but, because I did not see other people as being able to interact with me, I treated them as something to be manipulated (Blackman, 1999, p. 25)

Having a 'theory of mind' means having the ability to 'mind-read' (Baron-Cohen, 1995). It requires the individual to understand that they possess mental states, that others possess mental states, that these two sets of mental states can be independent from each other (because people have different desires, wants and beliefs) and that both sets of mental states can be independent of the real world (because we believe things which are not true).

Models of ToM

The mechanism by which ToM is proposed to develop has been the subject of much theory and debate. Two models are summarised here. One is to some extent an extension of the other. Both models have had significant influence and implication in the advancement of ASD/ToM theory and both are backed by considerable sound theoretical support.

Leslie (1987, 1988, 1995) introduced a two-layered model proposing that individuals must possess two types of representations. Primary representations are those things that *are* in the world e.g., tangible objects or things experienced or observed etc with the basis being in accuracy and truth. A second and more complex representation is the meta-representation, which consists of four elements:

Agent - *informational relation* – referent – 'action'

(person) e.g., *think, hope, pretend, wish, believe* – (object) – (behaviour)

Social understanding is therefore based on being able to attribute the informational relation between the agent and referent in order to predict/explain or engage in the behaviour. This model has formed the basis of a more complex model proposed by Simon Baron-Cohen (1995). Baron-Cohen conceptualises ToM as a cognitive mechanism that allows individuals to understand behaviour by utilising volitional interpretations (goals/desires), perceptual information (eye direction detection and shared attention) and epistemic mental representations (e.g., beliefs, thoughts, pretence etc). Baron-Cohen uses neurobiological evidence

for proposing a relationship between the deficits in ToM mechanisms and brain anatomy/insult.

The ability of ToM to differentiate between very similar behaviours has helped to explain some of the apparent anomalies in the field of ASD. For example, persons with ASD can use learn to use pointing behaviour to gain an object but fail to use pointing to share information or attention (Baron-Cohen, 1989). Similarly, individuals with ASD have been observed to use as many gestures as typically developing peers to 'manipulate' the behaviour of others (e.g., come here, go away) but fail to use gestures to influence the mental states (e.g., embarrassment, consolation) of others (Attwood, Frith, & Hermelin, 1988). Most other theories fail to explain the distinctions noted in everyday behaviour between those individuals with ASD and those without.

Research in the area of 'mind-reading' has been applied to the area of ASD with growing interest and while the social perceptual mechanism that underlies this theory is still debated, the hypothesis and mechanism of effect as evident in the manifestations of ASD is particularly encouraging (Happé, 1994). The triad of behavioural impairments in ASD is proposed to result from a fundamental impairment in this innate ability to attribute mental states to oneself and others in order to explain and predict human behaviour (Frith, 1989). The following section revisits the key manifestations of ASD in the light of this theory.

Features of ASD From A ToM View

Socialisation. If the person with ASD lacks the ability to think about thoughts (their own and others), then they would be unable to make meaning of their interactions with others. For example, a lack of eye contact indicates the person with ASD may be unable to use the social salience of eye contact to regulate, maintain or cease interaction. They would also be unaware of how to use eye gaze in others to gauge level of interest and social proximity. They would appear to lack sensitivity or empathy with others. They would be unable to take another person's point of view, fail to appreciate the feelings of others and often speak and act without regard to implicit social norms thereby exhibiting behaviour

which is seen to be socially inappropriate, callous, rude and unfeeling. They would not appear to consider the consequences of their actions in terms of reactions or thoughts of others. They would fail to use or understand deception, sarcasm and humour and would be unable to understand misunderstandings. They would show inflexibility in their interactions with others and would be unable or slow to vary their interactions with others when the context of a particular situation changed:

> It is very difficult for even a high-functioning autistic adult to know exactly when to say something, when to ask for help, or when to remain quiet. To such a person, life is a game in which the rules are constantly changing without rhyme or reason (Carpenter, 1992, p. 291).

Communication. In communication, individuals with ASD would be unable to determine what others do or do not *know*. They would start sentences and conversations part-way through and expect listeners to know what had already been privately considered. They would fail to use cues to enable the listener to orient themselves with respect to topic of conversation or memory. They would have a paucity of causal relationships in their speech and explanations. They would string together a number of statements or facts without reference to how one feature relates to another because they would fail to understand why or how things were connected. They would fail to comprehend the intent behind speech instead relying on the actual words used. For this reason, it is common to observe that the child with ASD is able to recognise words (particularly nouns) and have a high reading age, but their level of accompanying understanding or reading comprehension is significantly lower than expected. They would show evidence of pronoun reversal and a paucity of reference to mental states (e.g., knowing, belief) when providing descriptions:

> I didn't communicate by talking, not because I was incapable of learning to use language, but because I simply didn't know that was what talking was for. Learning *how* to talk follows from knowing *why* to talk and until I learned that words have meanings, there was no reason to go to the trouble of learning to pronounce them as sounds... I had no idea that this could be a way to exchange meaning with other minds (Sinclair, 1992, p. 296).

Restricted Imagination and Play. Behaviours like non-functional use of toys and lack of imaginative/pretend play are easier to comprehend in the light of ToM as they are all skills/behaviours which require meta-representational ability. In order to 'play' with a toy in a functional manner, one must understand what the function of the toy is purported to be. For example, a doll is assumed to represent a human and so we expect doll play to involve actions and verbalisations around 'human' behaviours e.g., dressing, eating, putting to bed. Similarly, toy cars are assumed to represent real cars and associated play would be expected to consist of driving the car to places and so on. Play therefore relies on a shared and implicit understanding that real objects (humans, cars) can be represented by other objects (dolls, toy vehicles) and imaginative play also relies on the understanding that real objects can be represented by non-related objects (e.g., pretending a banana is a telephone) or no object at all (e.g., talking to an invisible friend). Play, pretence, imagination and creativity require an understanding of implicit relationships between objects, an understanding of the collective social expectations for functionality of objects and relationships between objects/people, the ability of putting oneself into the position/mind of another and the use and manipulation of objects in ways other than how they appear in the real world:

> Lego blocks were not a tool from which I constructed something which my mind had pre-planned. As a small child, the feel and symmetry of these plastic interlocking blocks was all absorbing, and all I understood of their function was that they made patterns in long rods. (Blackman, 1999, p. 32).

Some aspects of the ASD condition are easier to comprehend in the light of ToM. In other aspects (including heightened anxiety, perseveration and extreme fear reactions), the connections are not so obvious. It is proposed here (and by others) that if one views their world without the depth of understanding required to reliably predict and explain the behaviour of others, one would not only feel detached or separate from their social environment but also interactions with others would become a source of anxiety:

> Because I live in an uncertain world, change of any kind was so incomprehensible that when anyone said, 'I think I might...' or 'I wonder

> if it would be best to....', my four-dimensional world unfolded like a paper streamer (Blackman, 1999, p. 156).

Consider the following hypothetical scenario: You are walking down the street and notice an individual cheerfully whistling as they come towards you. You make brief eye contact, you both smile and continue past. Now imagine that this individual walked into the nearest shop, pulled out a gun and shot innocent bystanders. The immediate shock and devastation that such an event would provoke would be accompanied over time with desperate attempts to rationalise and explain the unexpected behaviour of the passer-by. The longer term effects from experiencing or witnessing such an event would be distrust of others and distrust of one's own ability to read or predict the behaviour of others. This unease would contribute to heightened anxiety and avoidance – both common reactions to traumatic events. While extreme, this example serves as an analogy to illustrate how the world must appear to someone who cannot understand or predict the actions of others on a daily basis. The ASD behaviours that appear to typically developing people as bizarre e.g., self-stimulation, self-mutilation, rigid adherence to routine may serve the function of decreasing anxiety and/or escape/avoidance from anxiety-provoking situations:

> She used to wail like a banshee when she made a painto [painting error], even if it could be fixed with the stroke of a brush. It's not the ease of repair that counts if you're autistic, it's the simple fact of error, in a world that seems controllable only when things are done exactly according to rule (Park, 1992, p. 252).

Particular fears and phobias are considered irrational when the reaction one displays appears to be out of proportion to the actual object or situation observed. Such a judgement relies on our understanding or perception of the situation. Viewing seemingly irrational behaviours from a ToM context gives another perspective to the situation. For example, Tom displayed extreme and prolonged fear behaviours (screaming, running away, crying, hyperventilation) when video tapes were played. This behaviour had not always been evident but had worsened after the tape was rewound while being visually displayed on screen by a visitor to the house. One explanation for this behaviour in the light of ToM is the inability of the child with ASD to consider the implications of things not visually obvious.

For instance, the fast, backwards display of material had no reference to real life and thus was unexpected and unknown. Where there were clear indications as to the end of the tape when played forward, the markers were lost in the reversal. In effect, an object that was familiar – had a clear beginning and end, and progressed in a familiar sequence was suddenly unfamiliar and unknown. Displayed backwards, the imagery also no longer had any reference to reality adding to the sense of unfamiliarity.

Explanations about their own perceptions give new insight into behaviours that are mistakenly attributed to other reasons by observers. Lucy Blackman speaks about her own seemingly irrational fear to running water which was surmised by family members to be due to the splashing of the water into the bath/basin. Lucy states "splashing of water was not cause for alarm,... rather it was seeing water shooting from nowhere as it passed from the tap, and the sound of the fluid rush through the air that caused terror" (p. 7). In other words, it was a lack of understanding of things unseen (the source of the water) and the lack of an implicit understanding that turning on a tap made water flow from elsewhere combined with an audible sensation that contributed to a sense of terror.

There are a number of possible hypotheses generated with respect to each of these behaviours in terms of functional and behavioural principles. ToM offers new understandings and hypotheses for difficult behaviours in the area of ASD. The advantage with this theory of ASD is that it not only can account for the behavioural manifestations of ASD but also the preservation of primary representational skills (e.g., rote memory, savant abilities) and the above average IQ commonly viewed amongst the ASD population (Happé, 1994).

Deficits in one's ability to 'mind-read' are proposed to be unique to the area of ASD thereby offering a potential direction for causative research and intervention development. Current debates in this area tend to focus on discrepancies in cognitive functioning (e.g., Dahlgren & Trillingsgaard, 1996; Teunisse, Cools, van Spaendonck, Aerts, & Berger, 2001), issues of diagnosis (e.g., Ozonoff, Rogers, & Pennington, 1991) and levels of communicative ability (e.g., Peterson & Seigal, 1995, 2000). In most cases, replicated studies have found a poor level of

'mind-reading' ability in individuals with ASD compared with other groups of individuals.

Tests based on mental states have been at the forefront of research involving ToM in individuals with ASD. In particular, theorists have proposed that in order to test ToM, a task must be devised to capture what another person is thinking. This has been achieved through the creation of false belief tasks in which the subject is required to make inferences about the behaviour of others whose beliefs differ from objective reality (Dennett, 1978). For example, Wimmer & Perner (1983) created a simple changed- location false belief task that required observers to predict the behaviour of one actor (a doll) based on the 'actions' of another. Two dolls, Sally and Ann are observed together. Sally has a 'ball'. She places it in a basket and leaves the room. The child observes Ann remove the ball and hide it in a box. Sally returns to the room and the child is asked where Sally will look for her ball. This now classic test is known as the 'Sally-Ann task'. It requires the observer to appreciate that Sally does not *know* the ball has been moved because she did not *see* it being moved and therefore she must *believe* it is still in the basket where it was originally placed.

The majority of children with ASD fail to appreciate Sally's false belief. Instead of saying that Sally would look for the ball in the place she had originally put it (the basket), they instead state that she will look for it in the box where it really exists and where *they,* as the observer, saw it being placed. In other words, they fail to understand that Sally has a certain belief in her head which is different from that which they hold in their own head *and* they fail to understand that Sally's belief will guide her behaviour (i.e., where she will look for the ball). In contrast to the failure of children with ASD to anticipate Sally's behaviour based on her (false) belief, research has found that the majority of typically-developing children aged 4 years and 86% of Downs Syndrome subjects of low mental age understand the false belief in this task. These subjects correctly anticipated that Sally would look for her ball in the 'wrong' place ruling out simple cognitive deficits as an explanation for the ToM delays observed in children with ASD (e.g., Baron-Cohen, Leslie, & Frith, 1985; Perner, Frith, Leslie, & Leekham, 1989).

Daily Life Without a Theory of Mind

Most social interactions occur within a culturally defined set of behavioural norms and expectations. The individual with ASD has no access to or awareness of (at least initially) these shared social norms and thus their social behaviours appear deficient, unnatural, mechanistic and largely 'inappropriate' or contrary to expectations. For the same reason, communication appears to be devoid of intent and meaning. Individuals with ASD have a fundamental difficulty understanding that other people think. They also have difficulty with the *content* of that thought process and how those thought processes affect behaviour. If one was unable to conceptualise others as having minds that contain thought processes that lead to behaviours, people would appear to act in an extremely unpredictable manner. Moreover, actions and situations would occur without apparent reference to the context and things would appear to occur or happen without reason or explanation. Thus interactions with the world on a daily and ongoing basis would be unpredictable, erratic and disjointed:

> I felt disoriented rather than sympathetic [to the plight of others]. I was confused when the cornerstones of my world, these familiar coloured shadows among whom I lived, acted in an inexplicable way. As I was in the centre of a world which had neither cause or effect, this left me without a rational frame. (Blackman, 1999, p. 25).

Interactions with others would also be devoid of context and the individual with ASD would have limited awareness of the impact of their behaviour on others. Where some awareness of impact of behaviour on others is noted, it is often accompanied with anxiety over a lack of understanding about the specific aspects of behaviour which are causing disproval etc in others and a desperate attempt to grasp the right key to producing an accepting response. For this very reason, socially-mediated or intrinsic reinforcement – praise, smiles etc mean little to the person with ASD:

> I did not always understand that people were cross or pleased with me because of what I had just done. Therefore, for many years 'cause and effect' was very much a mysterious and variable phenomenon. In fact, people's emotions and praise simply did not impact on me at all. (Blackman, 1999, p. 39).

Where people with ASD have gained an awareness of the 'socialness' of others, they have also gained an awareness of 'loss of self':

> I cannot remember any time in my childhood when I thought of myself as being similar to other people in how GOD had constructed me (Blackman, 1999, p. 25).

Theory of Mind as a Mentalising Problem

The deficit in ToM in individuals with ASD is specific to *mental* representations. Individuals with ASD have shown greater abilities than normally developing peers with non-mental representations. For example individuals with ASD were able to successfully predict false belief tasks when using visual aids (Baron-Cohen, Leslie, & Frith, 1986; Leekham & Perner, 1991; Leslie & Frith, 1988; Leslie & Thaiss, 1992; Reed & Peterson, 1990; Zaitchik, 1990). Individuals with ASD sometimes describe their mental processing abilities entirely in non-mental (visual) representations:

> I think in pictures. Words are like a second language to me. I translate both spoken and written words into full-colour movies, complete with sound, which run like a VCR tape in my head. When somebody speaks to me, his words are instantly translated into pictures (Grandin, 1995b, p. 19).

To the detriment of individuals with ASD (many of whom are strongly visual) a lot of social interactions are audibly mediated, particularly in the educational environment. Education is predominantly verbal, as is our social behaviour and control of behaviour as we grow older. Along with experiencing overload, sensory over-stimulation, sensitivity or confusion, individuals with ASD also have to decode abstract language, verbal shortcuts, slang, innuendo, humour and sarcasm without a shared social understanding as to intent or expectation of the speaker. Today there is a growing realisation of the educational value in utilising non-mental representations (e.g., visual sequencing, social stories, pictures, maps, photos) to enhance learning among children with ASD.

Can ToM be Taught?

A theory about an inability in people with ASD to understand the concept of the 'mind' in relation to self and others lends itself to a proposed method of intervention for these individuals and begs the question - can theory of mind by taught? One may immediately presume that as human socialisation is so complex, the task of teaching someone to 'mind-read' would be virtually impossible. However, the above discussion shows that the areas presumed to be impaired in individuals with ASD can be conceptualised as a series of tasks around the ability to consider oneself (in mental terms) in relation to others.

To date, there have been limited attempts to teach children with ASD to 'read minds'. Research focused on teaching ToM techniques has been largely restricted to approaches teaching children with ASD how to pass tests of false belief (Pelios & Lund, 2001). Some studies have also demonstrated that individuals with ASD can attain competence in various discrete informational-state tasks, although maintenance and generalisation of acquired skills has been variable (Ozonoff & Miller, 1995). While this research is an important starting point, it has an experimental emphasis which is somewhat limited to demonstrating that individuals with ASD can be taught mental tasks.

Conceptualisation of an impaired ToM as a key deficit underlying the varied social, communication and cognitive behaviours of ASD gives rise to the idea that being able to teach an individual to 'mind-read' will provide an alternative pathway to understand their world and communicate their needs. An individual exhibiting aberrant behavioural manifestations of ASD may be taught alternative skills in order to facilitate interaction and communication with others. If so, one would expect to see a decrease in the use of particular errant behaviours as the function of these behaviours is replaced and an alternate method of understanding the social aspects of the world is enhanced.

In 1996, Hadwin, Baron-Cohen, Howlin and Hill undertook to determine whether children with ASD could be taught concepts of emotion, belief and pretence. The experimental group consisted of children with ASD aged between 4 and 13 years

with a language age of at least 5 years. Children received teaching in one of three areas: emotion, belief or play. Tasks included recognition of emotions in others, perspective taking and guided 'pretence' play. Improvements were significant in a short period of time and were maintained well after the intervention programme ceased. Based on this study, Patricia Howlin and colleagues (Howlin, Baron-Cohen, & Hadwin, 1999) have produced a guidebook for parents and educators entitled; *Teaching children with autism to mind-read; a practical guide.*

In this guide, attempts were made to formalise and make explicit, those mental tasks that are presumed implicit (know, desire, think). To minimise the conceptual complexity of mental tasks required, the authors divided their programme and book into three separate components; understanding informational states, understanding emotion and understanding pretence. Each component is ordered into five successive levels of understanding which increases in complexity as each stage is mastered. For example, understanding emotions starts with recognition of facial expression from photographs and proceeds sequentially to recognition of emotional expression from schematic drawing, identifying 'situation-based' emotion; identifying 'desire based' emotions and identifying belief based' emotions. Behavioural principles of utilising discrete trials, reinforcement of separate and sequential components, naturalistic teaching, errorless learning, intrinsic reinforcement and systematic training for generalisation are utilised throughout the programme to reinforce behavioural outcomes.

The content of the programme offered by Hadwin and Howlin and colleagues demonstrates the utility and value of initiatives based on ToM. To some extent however, the guide is prescriptive and some of the accompanying behavioral concepts and practices are technically challenging for the non-professional. There is the potential for the programme content to be applied rigorously and without a solid understanding of the ToM principles underlying the techniques. To date, there have been no follow-up studies to determine the effect of the guide with parents and educators although the authors encourage dialogue to this effect.

If people with ASD behave in a manner that is consistent with a 'mind-blind' world-view, then teaching others (e.g., parents and caregivers) to understand this

world-view would allow observers to interpret and reframe behaviours in terms of ToM deficits. The content of the programme outlined above appears to be based on the ability to make implicit social understanding explicit. Therefore, if parents/caregivers could learn to identify the implicit social expectations in a given situation and make them explicit, they could effectively enhance their child's social understanding and reduce the function of some challenging behaviours. It is proposed that teaching parents (and educators) the fundamental concepts of ToM will enable them to (a) reframe challenging behaviours in terms of ToM deficits and (b) devise alternative and effective strategies to increase functional behaviour and manage 'challenging' behaviours.

Descriptions by those who have ASD are consistent with ToM conceptualisations and lend support to the idea that we should endeavour to find a way to enhance the behaviour and social understanding of people with autism. Lucy Blackman writes of her own condition:

> My autism was not caused by or aggravated by lack of interaction in any way. My own lack of interaction was innate. However, watching the development of my sisters' children from the day of their birth, I speculate on the view of oneself as a person and the capability of that person to be complete if interaction with others is impaired... (p. 10).

Summary and Research Aims

While descriptions of autistic behaviours were made over 50 years ago, the significance and resulting upsurge in interest in these behaviours have not become apparent until this decade. By nature of the condition of ASD, associated behaviours are often severe and persist throughout the lifespan of the individual. Behaviours frequently impinge on family functioning and educational placements and are often resistant to consequence based intervention and typical behaviour management strategies.

Investigations have shown that parents of children with ASD face higher 'stress' levels than almost any other disorder. Alleviation of family strain and improving family functioning in those families with a child with an ASD are important

research goals and ones that have been identified as significant by the caregivers themselves. Despite the increase in professional knowledge in the area of ASD, parents of children with ASD are still left with a relative paucity of resources and guidance and are themselves a relatively unstudied group.

Personal communications with such parents reveal feelings of helplessness, inadequacy and a strong desire for knowledge and practical input to alleviate stressors involved in dealing with their children's condition. Following the tenets of action research (Banister et al, 1994), the act of obtaining knowledge is believed to create the potential for change. Therefore, it is hypothesised that parental behaviour and perceptions will change as a result of theoretical and practical training. Parent training programmes attest to the value of intervention in terms of both parent's emotional states and children's behaviour (e.g., Kaiser, et al., 1996) but child-focused intervention often leaves parents/caregivers without the skills and knowledge to effectively manage ongoing behavioural concerns.

The main purpose of this study is to equip parents/caregivers to be able to effectively and independently manage the challenging behaviours associated with ASD in order to decrease strain and enhance family functioning. It also aims to develop a short term intensive program in which parents are provided with information and techniques to improve parent-child relationships and maximise child development. An applied behaviour analysis approach requires that research be important, practical, effective and socially valid to the individual and society. Caregivers will identify behaviours that are considered challenging to functioning within their specific family and these behaviours will form the basis upon which skill building will be shaped and practised. In order to foster social support networks and maximise learning examples (e.g., Solnit, 1997), the proposed programme will be delivered in a group context.

ABA techniques are empirically validated for reducing challenging behaviours and have the advantage over traditional behaviour techniques of being non-aversive and focused on shaping functionally equivalent behaviour as opposed to applying consequences or managing contingencies. Part of the proposed programme will involve an ABA training component that will provide parents

with the knowledge and skills necessary to assess, treat and evaluate outcomes for their own child's target behaviours. Challenging behaviour is expected to decrease when ABA techniques are applied.

ToM provides an alternative view of the challenging behaviours associated with ASD. It requires no technical expertise or prior knowledge base. To date, there have been no recorded attempts to utilise ToM information as a parent-training tool with the aim of reducing challenging behaviour. This study will attempt to develop a component of the parent-training programme that features ToM information and will seek to determine the effect of providing this information to parents by considering the consequences on child behaviour. Challenging behaviour is proposed to decrease when ToM techniques are applied.

Assuming both techniques (ABA and ToM) can be effectively applied to challenging behaviours associated with ASD, an important aim of this study is to then determine the effect of each technique relative to the other. Of particular interest is whether either approach appears to have a strength relative to the other. The value and utility of applied behaviour analysis techniques is already well documented, therefore this approach is able to be used as a benchmark against which to measure the effectiveness of the ToM approach. Of particular interest is whether the provision of ToM information changes parental attributions about the child's behaviour and whether this approach is easily comprehended and able to be used by parents/caregivers to effectively manage challenging child behaviours. Also of interest is whether ToM information can enhance child development and family functioning. Outcomes on each of these parameters will be compared with the outcomes obtained using applied behaviour analysis techniques.

It is proposed that family functioning stress can be relieved by supplementing parenting skills with specific information aimed at reducing challenging behaviours associated with ASD. It is further proposed that empowering parents/caregivers to effectively manage child behaviour will result in positive and measurable child and parent outcomes. In terms of child behaviours and as already outlined, challenging behaviours are expected to decrease. It is also hypothesised that *enhanced adaptive functioning* will be an indirect effect of

intervention. For example, in utilising an applied behaviour analysis approach, socially unacceptable behaviours are replaced with functionally equivalent and appropriate behaviours thereby indicating that adaptive functioning should increase as challenging behaviour decreases. Similarly, providing an alternative view of challenging behaviours associated with ASD by providing ToM information would also be expected to enhance adaptive functioning by providing an alternative pathway to social understanding. In order to demonstrate the validity of the proposed training programme in the field of ASD, decreased challenging behaviour and increased adaptive behaviour will be measured in each of the three core areas of ASD.

In terms of parent outcomes, it is hypothesised that caregivers will be able to effect positive change in those behaviours which are identified as problematic in each specific family context. Successful management of difficult behaviours would be expected to result in parents/caregivers reporting changes in attitude about child behaviour and increased beliefs in their own parenting abilities. Reports of family stress and strain would be expected to decrease. Social validity is essential to applied research and as such, one final objective of this study will be to give the parents/caregivers (and families) a chance to comment on process issues and their experiences as participants.

CHAPTER 2

Methodology

In this section, participant details, experimental design and statistical procedures are described. The content of the parent-training programme, 'Recipe for Rainbows', is outlined and experimental measures and procedures are detailed.

Participants

Letters were sent to the local branch of the Autistic Association of New Zealand Inc, Parent to Parent, CCS and Child Development Centre to invite families to participate in the study (letter – Appendix A). Parents referred themselves for involvement in the training programme. They were told that the study had been designed to determine the effects of two different methods of training that aimed to help parents manage the challenging behaviours associated with ASD. Participants were also informed that they would receive training in both methods and that group allocation would determine the order of training presentation. Interested participants were sent an outline of the study and a consent form (Appendix B).

Ten families formed the experimental group. Participants consisted of a parent-child dyad. All parents met the following experimental criteria: (a) a commitment to attend nine group sessions (two hours duration each) at a set venue; (b) willingness to receive training in specific techniques and plan, implement and assess behavioural outcomes with their child; (c) willingness to maintain written records of target behavioural parameters and (d) consent to data being gathered, collated and analysed for research purposes. In addition, all children were (a) aged between two and ten years; (b) had received a diagnosis from an independent health professional which placed them within the autistic spectrum of disorders; and (c) exhibited at least three definable problem behaviours consistent with Autistic Spectrum Disorder diagnosis (DSM-IV TR; American Psychiatric Association, 2000).

All parent-participants were mothers and primary caregivers. In five cases, the mother was a fulltime caregiver at home. Four mothers were also studying or working part-time. One mother was in a self-employed business. Six parent-participants described their family ethnicity as New Zealand Caucasian, two families were English-New Zealand, one was Tikanga Māori (culturally Māori) - New Zealand Caucasian and the remaining family was Chinese-New Zealand. In this final family, English was a second language for the mother. The children had received most of their education in New Zealand and were fluent in both Chinese and English. Nine mothers described their family in nuclear terms (mum, dad and child/children). In the remaining case, the family had contact with their husband/father twice a year as he resided and worked overseas. Nine fathers were in full-time or self-employment. One parent chose to bring a support person. This person did not participate in any formal testing or record keeping.

The child-participants were two girls and eight boys. The children ranged in age from 47 months (3 years, 11 months) to 107 months (8 years, 11 months) with an average age of 72 months (6 years). Eight children were described as New Zealand (Caucasian), one child was Māori and one, Chinese-New Zealand. Five children had been diagnosed with Asperger's Syndrome, four were described as ASD and one had received a diagnosis of autism. The majority of children had been diagnosed when they were between two and four years of age. Two boys who received diagnoses of Asperger's were not diagnosed until age six years. Nine child-participants had siblings and seven participants were the youngest child in the family.

The two girls were the two youngest participants and both attended mainstream early childhood education centres. Both received teacher-aide support between 3-4 hours per week. Seven of the remaining children attended mainstream primary schools. One child attended a special unit within a mainstream primary school. This child received full-time teacher-aide funding under the Ongoing and Reviewable Resourcing Scheme (ORRS). All the other boys received some level of government funding under ORRS or Transitionary Ongoing Resourcing Scheme (T-ORS) and had teacher-aide resourcing between 10-20 hours per week (average 12.6 hours per week). One child was removed from a mainstream

primary school and home-schooled during the course of the programme following ongoing unresolved educational issues.

Group Assignment

Participating families were assigned into two condition groups (n = 5) based on the availability of the caregivers to attend weekly day or evening training sessions. The two groups met at a venue and time decided upon by the participants. The day group (Group One) met for training sessions in a participant's home. The evening group (Group Two) met in a local community facility. The *location* of training is unlikely to have confounded treatment outcomes as both groups received the same programme material (albeit in a different order).

Initial group placement determined the order of training. Group One received applied behaviour analysis training followed by ToM training, Group Two received the opposite order of presentation.

Both groups consisted of five mother-child dyads and each contained one girl and four boys. In Group One, the children's ages ranged from 3.11 years to 8.6 years with an average age of 5.7 years. In Group Two, the children's ages ranged from 4.11 years to 8.11 years with an average age of 6.3 years. There were no significant differences in age between the two comparison groups (t_{crit} = n.s; $p<0.05$). Individual participant data are summarised in Table 1.

Table 1

Experimental Group Participant Details

Child	Gender	Age (yrs)	Ethnicity	Diagnosis	Family culture	Age at diag. (years)	Number in family	Place in family	Family Employment Situation	School	Hours support at school/wk.	Behaviour
Damon	M	5.6	NZ	Asperger's	New Zealand Caucasian	3.6	Mum & Dad, 1 child	1/1	Dad on farm, Mum at home	Mainstream Primary School		1. Clothes off 2. Lack of comm. around social situations 3. Restricted food range
Fern	F	3.11	NZ	Autism Spectrum Disorder	New Zealand Caucasian	3.6	Mum & Dad, 2 children	2/2	Dad - own business, Mum at home	Mainstream Kinder-garden		1. Interrupting conversation 2. Non-attention 3. Mannerism - hand waving
Piripi	M	5.3	Maori	Autism Spectrum Disorder	New Zealand Caucasian & Tikanga Maori	3	Mum & Dad, 3 children	1/3	Dad employed outside Ham, Mum - working part-time	Mainstream Primary School	10	1. Turning TV on/off and hitting TV 2. Policing/hitting siblings 3. Taking Clothes off
Hugh	M	8.6	Chinese New Zealand	Autism Spectrum Disorder	Chinese New Zealand - English second language	3.6	Mum, 2 children. Dad not living in family home	2/2	Dad living in Taiwan. Family get together twice/year. Mum at home	Mainstream Primary School	10-12	1. Anger - tantrums 2. Non-approach to homework 3. Restricted food range
Flynn	M	6.11	NZ	Autism Spectrum Disorder	New Zealand Caucasian	4	Mum & Dad, 6 children	6/6	Dad employed, Mum at home. Two siblings overseas.	Mainstream Primary School	10	1. Rigidly demanding Mum's time 2. Tantrums 3. Rigidity - non-consideration of alternatives

Table 1 continued

Child	Gender	Age (yrs)	Ethnicity	Diagnosis	Family culture	Age at diag. (years)	Number in family	Place in family	Family Employment Situation	School	Hours support at school/wk	Behaviour
Kyle	M	7.4	NZ	Asperger's	New Zealand Caucasian	6	Mum & Dad, 4 children	4/4	Both parents in own business.	Mainstream Primary School	16	1. Anger reactions to situations. 2. Over-reaction to interactions with siblings. 3. Running away
Bryan	M	6.2	NZ	Asperger's	English/ New Zealand	3.9	Mum & Dad, 2 children	2/2	Dad on farm, Mum at home/study	Mainstream Primary School	22.5	1. Lack of morning routine 2. Non-compliance/ tantrum to instruction 3. Obsession with electrical appliances
Eliam	M	8.11	NZ	Asperger's	New Zealand Caucasian	6	Mum & Dad, 3 children	3/3	Dad unemployed, Mum studying.	Mainstream Primary School and homeschool.		1. Non-compliance/ anger reaction 2. Suicidal thoughts/ideation 3. Putting objects in mouth
Amy	F	4.11	NZ	Asperger's	English/ New Zealand	2	Mum & Dad, 2 Children	2/2	Dad on farm, Mum at home.	Mainstream Early Child-hood	3	1. Non-compliance/ tantrum 2. Non-sleep 3. Restricted food range
Elliot	M	5.8	NZ	Autism	New Zealand Caucasian	3.6	Mum & Dad, 3 children	2/3	Dad in full-time employment, Mum at home & casual wk	Special unit within Mainstream Primary School	Full cover	1. Non-compliance/ tantrum 2. 'Trashing' - tipping all toys onto floor 3. Smearing food

Note. All participant names have been anonymised to protect identity.

Experimental Design

Single Case Research

The current study took the form of a single case, or single subject, design (Barlow, 1974; Barlow & Hersen, 1984; Hersen & Barlow, 1976; Kazdin, 1973; Wilson, 1995). This design was chosen on the basis of (a) a small sample pool and implications of small sample size for group comparison studies; (b) the strengths of the single subject design for assessing change within individuals and its relevance to the aims of this study and (c) ethical considerations.

Small sample pool. The Waikato area has a conservative population estimate of 350,000 (Statistics New Zealand, 2002). Given the earlier prevalence rate of 0.9% for the range of ASD conditions one could expect ASD to affect over 3150 individuals in the Waikato. However, as already outlined, it is unlikely that some high functioning individuals have been or are considered in need of diagnostic services. Therefore, if reverting to the more conservative figure of 0.03-0.04%, the potential subject pool is severely truncated to around 105-140 individuals. This pool is further reduced when considering that this figure applies to individuals throughout the age range and the target population in this study was children aged between two and ten years.

The local branch of the Autistic Association of New Zealand Inc. has around 130 families represented. While based in Hamilton, it draws families from a large geographical region encompassing the greater Waikato, Thames and King Country regions. This restrictive sample pool has a number of implications for the choice of experimental analysis. Group comparison designs require matching of subjects on a variety of criteria (e.g., mental age, chronological age, gender) which would further reduce the potential sample pool and small sample sizes increase the risk of type II errors (i.e., failure to reject the null hypothesis when it is in fact false). Group comparison designs also tend to obscure details of changes within individual parameters of interest.

Strengths of single case designs. Single case designs have strengths when dealing with small sample sizes and when applied to analysis of the clinical utility of individualised treatment programmes (Baer, Wolf, & Risley, 1968). In this study, we were interested in individual (and small group) outcomes. Repeated demonstrations of training effect using multiple baseline designs allow discriminative analyses of results to determine the effect of the programme on behaviour and the respective role of training components. The visual analysis of data within intra-subject designs also enables viewers to determine the clinical significance of change.

While seen to be a weakness of designs which do not have independent control groups by some, the onus on the researcher in single subject experimentation is often quite demanding, requiring evidence of change in the behaviour of all individuals:

> In the visual analysis of graphed data as in single subject research, differences between baseline and experimental conditions have to be clearly evident and reliable for a convincing display of stable change to be claimed. In effect this sort of demonstration would probably have to be more powerful than that required to produce a statistically significant change (Parsonson & Baer, 1978, p. 112).

Ethical considerations. In order to demonstrate experimental control, group comparisons require that a separate control group is maintained or that the experimental groups have a treatment component with-held. These design options which place restrictions on access to treatment raise ethical concerns. Families with children with ASD face significant stress. With-holding treatment or a component of treatment in order to demonstrate experimental control presents a situation of added strain and risk for the family. This is perhaps more so in studies like this one as the efficacy of the applied behaviour analysis component of the treatment programme has already been sufficiently well established.

In this study, a multiple component design (Gast, Skouge, & Tawney, 1984; Parsonson, 1979) with a multiple baseline over two comparison groups is used to analyse the effect of training components on child behaviours. Within-subject

analyses using repeated measures across behaviours (Shaughnessy & Zechmeister, 1997) is used to analyse the effect of the treatment components/package on the identified target behaviours. Experimental control is demonstrated using a multiple-baseline design across behaviours and groups.

Statistical Procedures

Statistical analyses are used on occasion during this study to determine the significance of change noted between group means and participant behaviours (Kazdin, 1984). Independent t-tests are used to evaluate the significance of differences between the treatment groups/components and dependent t-tests are used to examine differences within participant data (Runyon & Haber, 1984). Confidence limits for rejecting the null hypothesis (of no differences between data sets) are set at the 5% level ($p<0.05$).

Programme Content

The programme consisted of nine sessions which were held over a nine week period. Eight of these sessions covered the course components – applied behaviour analysis and ToM. The two components each comprised of four sessions and are outlined below. Group One began their programme with the applied behaviour analysis (ABA) component while Group Two began with the ASD Specific Information (ToM) component. At session five, each group began the alternate (second) component of instruction. For each treatment component, the structure of presentation was similar: the first two sessions were largely instructional and the remaining two sessions focused on practice and feedback. Session nine consisted of participant feedback for all target behaviours and instruction in behaviour maintenance and self-management (Dixon, Moore, Hartnett, Howard, & Patrie, 1995; Sanders & Dadds, 1993; Sanders & James, 1983; Stahmer & Schreibman, 1992). A full copy of the programme is in Appendix C.

Applied Behaviour Analysis. The applied behaviour analysis training component consisted of four sessions. In session one, the function of behaviour was outlined and the view of behaviour as a means of communication was established. The applied behaviour analysis approach to behaviour was introduced by engaging participants in a three step process of (a) determining the function underlying a particular behaviour (Carr et al., 1994; Durand, 1986 as cited in Durand, 1990), (b) identifying current practices that increase or decrease behaviour and (c) understanding the effects of reinforcement and punishment on behaviour. Session two consisted of functional communicational training i.e., teaching appropriate responses (functional replacement) and making problem behaviour non-functional. Participants devised a plan using their first identified target behaviour and implemented the plan as a homework exercise over the following week. Sessions three and four consisted of review, feedback and evaluation of practice. Each of the three target behaviours was sequentially introduced over sessions two to four and each became the focus of further planning and practice. Instruction and intervention took place without specific reference to the condition of ASD.

Theory of Mind. In order to remove the perception that higher knowledge was required to understand the 'theoretical' and abstract nature of ToM and in order to avoid confusion over the content of training based on ToM (some personal communications prior to the study revealed that people thought ToM was 'mind-reading'), this section was renamed 'ASD Specific Information' and the concept of ToM was referred to as 'social understanding'.

Sessions one and two were again instructional in nature. Session one outlined how an understanding of ASD would enhance perceptions of behaviour. Theory of Mind was introduced by looking at the deficits inherent within ASD in comparison to normal child development. The benefits of social understanding were outlined and parents considered the implications of a lack of social understanding for their child. In session two, parents were introduced to the idea of providing an alternative pathway in order to facilitate their child's social understanding. A plan for intervention was introduced for the first target behaviour. Parents were taught to make their intentions

explicit, how to teach their child new skills/behaviours and how to utilise visual prompts to aid interactions, reinforce desired behaviour and teach the child to recognise the effects of their behaviour on others. Sessions three and four consisted of discussion of the previous weeks' outcome and devising plans of intervention for target behaviours two and three.

Measures

Target Behaviour. It has been ascertained that parents are able to reliably observe and report behaviour occurrences (Chamberlain & Reid, 1987). Accordingly, target behaviours were monitored and recorded (Appendix D) on a daily basis by the parent. The majority of behaviours were recorded as 'number of occurrences' or frequency. Time sampling was used for recording purposes when behaviours were continuous or occurred with high frequency (e.g., playing with electrical appliances). Where behaviour was challenging in terms of non-occurrence (e.g., lack of sleep, restricted food range, lack of morning routine), individualised recording methods were devised with a focus on quantifying positive behaviours. For example, restricted food range was recorded as number of attempts to try new foods. Lack of morning routine was recorded as number of times a set of daily tasks was completed. Total weekly behaviours were recorded and average daily scores were calculated.

Adaptive Behaviour. Adaptive behaviour was chosen as a validated behaviour measure and was assessed using a standardised instrument: the Vineland Adaptive Behavior Scale – Interview Edition, Survey Form (Sparrow, Balla, & Cicchetti, 1984). The Vineland Adaptive Behavior Scale (VABS) was derived from the Vineland Social Maturity Scale (Doll, 1965) and measures adaptive behaviour in four domains: communication, daily living skills, socialisation and motor skills. The first three domains were assessed in this study and these items were administered during a semi-structured interview with the parent.

Adaptive behaviour is defined as the performance of daily activities required for personal and social sufficiency and is based on three important principles:

1. Adaptive behaviour is age-related and thus becomes more complex as the individual ages. Different skills and behaviours gain priority at different stages of the individual's development and growth.
2. Adaptive behaviour is defined by the expectation or standards of other people and is culture-specific. The VABS was based on a United States standardisation sample.
3. Adaptive behaviour is defined by typical performance as opposed to ability.

The VABS was standardised against a sample of 3000 disabled and non-disabled individuals. Normative data are provided in the manual for a wide range of age groups ranging from birth to 18 year 11 months. This measure has established validity (construct, criterion-related and content) and reliability (e.g., test-retest range 0.76-0.93 cited in Sparrow et al., 1984) and is strongly recommended for use with specialised populations including individuals with ASD (Perry & Factor, 1989). There are a number of additional normative data sets available for specialised populations including norms for the ASD population (Carter, Volkmer, Sparrow, Wang, Lord, Dawson, Fombonne, Loveland, Mesibov, & Schopler, 1998) which was utilised in this study.

Attributions. On the basis of attribution research (e.g., Jones & Davis, 1965; Kelley, 1967; Stratton, 1997), a simple rating scale was devised to measure the four major factors of attribution: consistency or stability of behaviour, uniqueness/ distinctiveness, dispositional versus situational and control. The rating scale consisted of eight questions and utilised a seven-point Likert scale format as below (for the full scale – see Appendix E):

Consistency/stability	Q1 & 2*	1 = no consistency, 7 = high consistency
Uniqueness/distinctiveness	Q3* & 4	1 = no uniqueness, 7 = high uniqueness
Situational versus dispositional	Q5 & 6*	Below 4 = situational, Above 4 = dispositional

Controllability	Q7 & 8*	1 = no control, 7 = high control

Note. * = Reverse score.

Parents were asked to recall a recent incident of their child engaging in undesirable behaviour (e.g., Freeman, Johnston, & Barth, 1997; Gretarsson & Gelfand, 1988; Johnston & Freeman, 1997) and to respond to the scale focussing on that incident. Scores were combined to give an indication of parent attributions in each domain. The utility and limitations of this measure are discussed in the results section - Chapter Five.

Parent Locus of Control. The Parent Locus of Control (PLOC - Campis, Lyman, & Prentice-Dunn, 1986) is a unique self-rating measure that seeks to ascertain parents views/beliefs about parenting and child behaviour issues. The PLOC comprises of five factors: parental efficacy, parental responsibility, child control over parent's life, parental belief in fate/chance and parental control of child's behaviour. The parental control scale was found to be most effective for differentiating between parents with/without difficulties.

The PLOC has been assessed to have satisfactory reliability, construct and discriminative validity (Fischer & Corcoran, 1991). No test-retest stability data were reported. As the fate/chance factor failed to discriminate between parents with/without parenting difficulties, the authors recommend elimination of this scale and this advice has been followed when administering the PLOC in this study.

There are some limitations with the PLOC measure. Most notably, it does not have clear norms for large sample groups. There is also a lack of normative data for a range of child ages and stages of development. Nevertheless, Lefcourt (1991) commends the instrument for the design and care in development and recommends that the PLOC holds considerable promise as a unique and socially valid measure of parenting issues and beliefs.

Family Stress. The Questionnaire on Resources and Stress for Families with Chronically ill or Handicapped Members (QRS) was developed by Holroyd in 1987 and was designed to measure stress in families who are caring for ill or disabled relatives.

The full version of the QRS consists of 221 questions divided into fifteen different scales. The scales are contained within three broad domains as follows:

A. Personal Problems for the Respondent		
1.	Poor health/mood	11 questions
2.	Excess time demands	14
3.	Negative attitude towards child (condition)	23
4.	Overprotection/dependency	13
5.	Lack of Social Support	10
6.	Overcommittment/martyrdom	7
7.	Pessimism	13
B. Family Problems		
8.	Lack of family integration	23
9.	Limits on family opportunity	9
10.	Financial problems	17
C. Problems for the Child/Individual		
11.	Physical incapacitation	14
12.	Lack of activities for child	6
13.	Occupational limitations	7
14.	Social obtrusiveness	7
15.	Difficult personality characteristics	32
16. Validity scale		15
	Total	**221**

The QRS has undergone a number of validation studies, primarily on families with children and adolescents with a variety of physical, intellectual and developmental disorders. Validity data from a wide range of different population groups and cultures (including New Zealand) suggest it may be applicable to a wide range of population groups (Holroyd, 1987; Wilton & Renaut, 1986).

Scores above a T score of 70 are considered significant (T score < 60 = 1 standard deviation compared with the normal sample) and may be interpreted with the help of descriptions supplied in the manual. A profile sheet allows comparisons of scores of

individual respondents and their family to average scores achieved by respondents whose family members are all healthy/non-disabled. Some members of the original sample group included families with children with autism and while some research is included within the manual using samples with individuals with ASD, no ASD norms are provided in the manual. However, some research using the QRS has produced stress profiles for families of children with ASD (e.g., Holroyd & McArthur, 1976; Kodaki & Inanami, 1978; Koegel, Koegel, Hurley, & Frea, 1992). These profiles are used for comparative analyses in chapter seven.

A 66 item short-form questionnaire is also available but is recommended for broad screening purposes only. Thus, while somewhat tedious to administer, the information contained within the complete questionnaire is more appropriate/relevant for clinical purposes and research comparisons and is therefore utilised in this study.

Procedure

Baseline Measures and Records

Pre-baseline. Prior to the course commencing, participants were interviewed to gather relevant background information regarding child and family variables (interview form – Appendix F). In consultation with parents/caregivers, target behaviours in the three core areas of ASD (social, communication and interest range behaviour) were identified. Behaviours were prioritised by parents for order of intervention and assessed using observation, interview and rating scales (Motivation Assessment Scale (adapted) - Durand, 1986 as cited in Durand, 1990) to ascertain baseline form and function of behaviour. Target behaviours were described and recording parameters (e.g., frequency, duration, intensity) negotiated with parents.

Baseline. Baseline measures (VABS, PLOC, Attribution Scale, QRS-R) were completed and daily behavioural records for the three target behaviours were commenced. In order to allow comparisons across groups using multiple baseline data, the two comparison groups started gathering baseline data at different times.

Group Two participants recorded 14 days of baseline data before the course began compared with Group One who recorded seven days of baseline data. Both groups continued to record behavioural outcomes on a daily basis throughout the programme.

Programme administration and training. Participants attended nine training sessions over a nine week period. The weekly sessions were two hours in duration. Instruction and practice in two course components (applied behaviour analysis and ASD-specific information) were presented over a period of four weeks each. As previously outlined, the first two sessions in each component were largely instructional. The second two sessions were practice oriented and consisted of feedback and planning with a focus on one target behaviour per week. At sessions five, each group began the alternate component instruction. The final session comprised of feedback and instruction on self-management and maintenance of new behaviours. A summary of the programme procedure is outlined in Table 2.

During the group sessions, participants were required to use their previous observational data to assess the identified target behaviour and formulate relevant treatment plans. During the between-session intervals, participants were required to implement the plan they had devised and maintain daily behaviour records. At the following session, participants discussed and evaluated treatment outcomes and procedures. The researcher met once a fortnight with individual parents on an informal basis, in the parent's home, to discuss and evaluate the plan/progress and offer support where required.

Table 2:

Outline of programme administration.

Session	Group One	Group Two
	Phase A **Applied behaviour Analysis (ABA) / ASD specific Info (ToM)**	
1	ABA 1 Observe target behaviour 1 Record ABC	ToM 1 Observe target behaviour 1 Record ABC
2	ABA 2 Plan & implement behaviour 1. Observe/record behaviour 2.	ToM 2 Plan & implement behaviour 1. Observe/record behaviour 2
3	ABA 3 Feedback behaviour 1 Plan & implement behaviour 2. Observe/record behaviour 3.	ToM 3 Feedback behaviour 1 Plan & implement behaviour 2. Observe/record behaviour 3.
4	ABA 4 Feedback behaviour 2 Plan & implement behaviour 3.	ToM 4 Feedback behaviour 2 Plan & implement behaviour 3.
	Midpoint Assessment	
	Phase B **ASD specific info (ToM) / Applied behaviour Analysis (ABA)**	
5	ToM 1 Feedback behaviour 3 Observe target behaviour 1 Record ABC	ABA 1 Feedback behaviour 3 Observe target behaviour 1 Record ABC
6	ToM 2 Plan & implement behaviour 1. Observe/record behaviour 2	ABA 2 Plan & implement behaviour 1. Observe/record behaviour 2.
7	ToM 3 Feedback behaviour 1 Plan & implement behaviour 2. Observe/record behaviour 3.	ABA 3 Feedback behaviour 1 Plan & implement behaviour 2. Observe/record behaviour 3.
8	ToM 4 Feedback behaviour 2 Plan & implement behaviour 3.	ABA 4 Feedback behaviour 2 Plan & implement behaviour 3.
9	Maintenance of new behaviour and self-management. Feedback behaviour 3 **Endpoint Assessment & Evaluation**	

Midpoint assessment. During the week after session four, baseline measures (VABS, PLOC, Attribution Scale, QRS-R) were repeated in order to ascertain the effect of the first training component. At this stage, Group One had completed applied behaviour analysis training and practice and Group Two had completed the social understanding - ToM component.

Endpoint assessment & evaluation. At the conclusion of the course (i.e., after session nine), baseline measures (VABS, PLOC, Attribution Scale, QRS-R) were repeated in order to determine treatment effects over both course components. Parent-participants were also asked to fill in an evaluation form (Appendix G) to gauge the level of satisfaction with the programme and to determine the parent's perceptions of the social validity of behaviour changes (Hawkins, 1991; Wolf, 1978).

Post-testing & maintenance. Base-line measures (VABS, PLOC, Attribution Scale, QRS-R) were re-administered at both short-term (ten-week) and long-term (seven-month) follow-up sessions. These sessions were conducted in the parent's homes. Prior to each follow-up session, parents were asked to complete behaviour records over a one-week period. Each of the three target behaviours was observed and recorded using the behavioural parameters utilised throughout the programme.

The specific behaviours targeted by each parent and the applied behaviour analysis/social understanding strategies applied, will be presented as part of the results section which follows.

Overview of Results

The results of this programme have been divided into six chapters. Chapters 3 and 4 focus on child behaviour outcomes. Chapters 5 and 6 look at parent outcomes: attributions and parent locus of control. Chapter 7 focuses on the issue of family stress and Chapter 8 summarises parent views/evaluation of the programme and research process.

Chapter 3 investigates the effect of the programme on the individual target (problematic) behaviours identified for each child in the experimental group. A summary of the behaviour changes for Group One is presented after a detailed analysis and discussion of the behaviour changes noted for each child. The effect of the two course components on Group One child-behaviour outcomes is discussed at the end of this section. Group Two data are similarly presented and described and behaviour changes are summarised. Course component effects are discussed for Group Two child-behaviours. A summary of the results for all child-participants is discussed and followed by a comment on the comparative effect of the course components on behavioural outcomes.

Chapter 4 focuses on the effects of the programme on child *adaptive* behaviour. The combined experimental group outcomes are compared with supplementary norms for individuals with ASD and 'typical' (age-equivalent, non-ASD) individuals. Changes in adaptive behaviour domains (communication, daily living skills and socialisation) are discussed and gains over the course of the programme are described and considered. Individual results are discussed with careful attention given to gains made over the course of the nine week programme. Changes in adaptive behaviour domains between groups are discussed and summarised.

Chapter 5 looks at the effects of the programme on parent attributions about child behaviour. Group results are outlined and differences are examined. Changes in attributions over each course component are compared and discussed. Results are discussed with reference to previous research outcomes.

Chapter 6 considers the effects of the programme on parent perceptions and beliefs about parenting efficacy, control, responsibility and child control of the parent. Group results are discussed for each aspect of parent locus of control and summarised.

Chapter 7 investigates the effect of the programme on family resources and stress. Respondent (mother), family and child characteristics are examined and summarised. A comment is made about the effect of the programme on experimental group stress

profiles. Individual stress profiles of participants are examined and data are summarised for group comparisons. The results are discussed with reference to previous research outcomes and a proposal of the stress profile of New Zealand parents raising a child with ASD is presented.

Chapter 8 gives the parent-participants a 'voice' and encourages comment on the programme content and research process. Part 1 focuses on the evaluation of the two course components and parental preference is examined. Part 2 focuses on parent perceptions of behaviour change and invites participants to comment on their attributions of the behaviour changes observed. Part 3 considers parent's views and comments on other programme features including group format, social support and programme length/intensity. An overall summary of findings concludes this chapter.

CHAPTER 3

Individual and Group Behaviour Change

The following section is a presentation of the results of the behaviour changes in each child. With reference to accompanying graphs, each child's behavioural outcomes are discussed in detail. The discussion is divided into separate analyses for each treatment group. Each group discussion is followed by a summary of group behaviour changes and a comparison of the effects of the two programme components. A general discussion of behaviour change and a summary of programme effectiveness follows at the conclusion of the chapter.

Data were recorded by parents on a daily basis. Data are presented in graphic form as average daily data per week so each data point depicted on the graphs actually represents seven days' worth of data records. Throughout this chapter, behaviours are analysed using trend and level comparisons as outlined in Tawney and Gast (1984). Average daily data over a week give a clear depiction of the trend of behaviour change. It is acknowledged that some information is lost when using average data; however the benefits of clear visual representation and trend analysis is believed to outweigh these disadvantages, particularly in engaging parents in understanding data patterns for their own children. Pre-programme records are depicted by the notation of P1 and P2 (i.e., one and two weeks before programme commencement). The programme began at week 1. Intervention for each phase is depicted by a broken dotted line.

In implementing this training programme, parents were encouraged to devise their own strategies and techniques. Each parent was given the same programme information and the trainer had limited input into the actual techniques utilised with each child beyond guiding the parent to view the behaviour in terms of the specific information presented. While there is some utility in describing specific techniques utilised by individual parents, it is not the focus of this research to exhaustively detail the parent's choice of intervention. Rather, the emphasis was on providing specific

information and determining whether parents could use this information to effectively change child behaviour. As such, the following section does not include the entire range of techniques utilised by parents at each stage of the programme. Specific techniques are detailed at times for illustrative purposes.

Data Description - Group One

In this section, the data from Group One will be examined. In this group, the programme consisted of a variable period of baseline measurement over behaviours, followed by the applied behaviour analysis (ABA) component (A) and then the Theory of Mind (ToM) component (B). Follow-ups took place ten weeks and seven months after the conclusion of the programme. Discussion concerning the applied behaviour analysis component will be more detailed compared with the ToM component in this section as the design of the study meant that this first group was able to collect more applied behaviour analysis data over the course of the programme. This focus will reverse in the discussion of Group Two data. Behaviour change in each target area will be discussed for each child.

Damon

Behaviour 1 – Clothes removal while toileting. The occurrence of behaviour whereby Damon took his clothes off while toileting and refused to put them back on was of major concern to his parents for social and personal safety reasons. The data presented in Figure 1a show a decelerating-improving trend in the average number of times Damon removed his clothes per day during baseline. Working on the assumption that the behaviour was fulfilling a sensory function (to cool himself), intervention (Damon was given a battery-operated fan to operate while in the bathroom and was rewarded for successful re-dressing before exiting the bathroom) during the ABA phase (A) of the programme resulted in a reduction of behaviour at lower rates compared with baseline until nil levels were reached. A nil rate of behaviour was maintained during the ToM phase of the programme. A high rate of behaviour was noted during a probe at the 18 week follow-up but returned to nil levels at the long-term (41 week) follow-up.

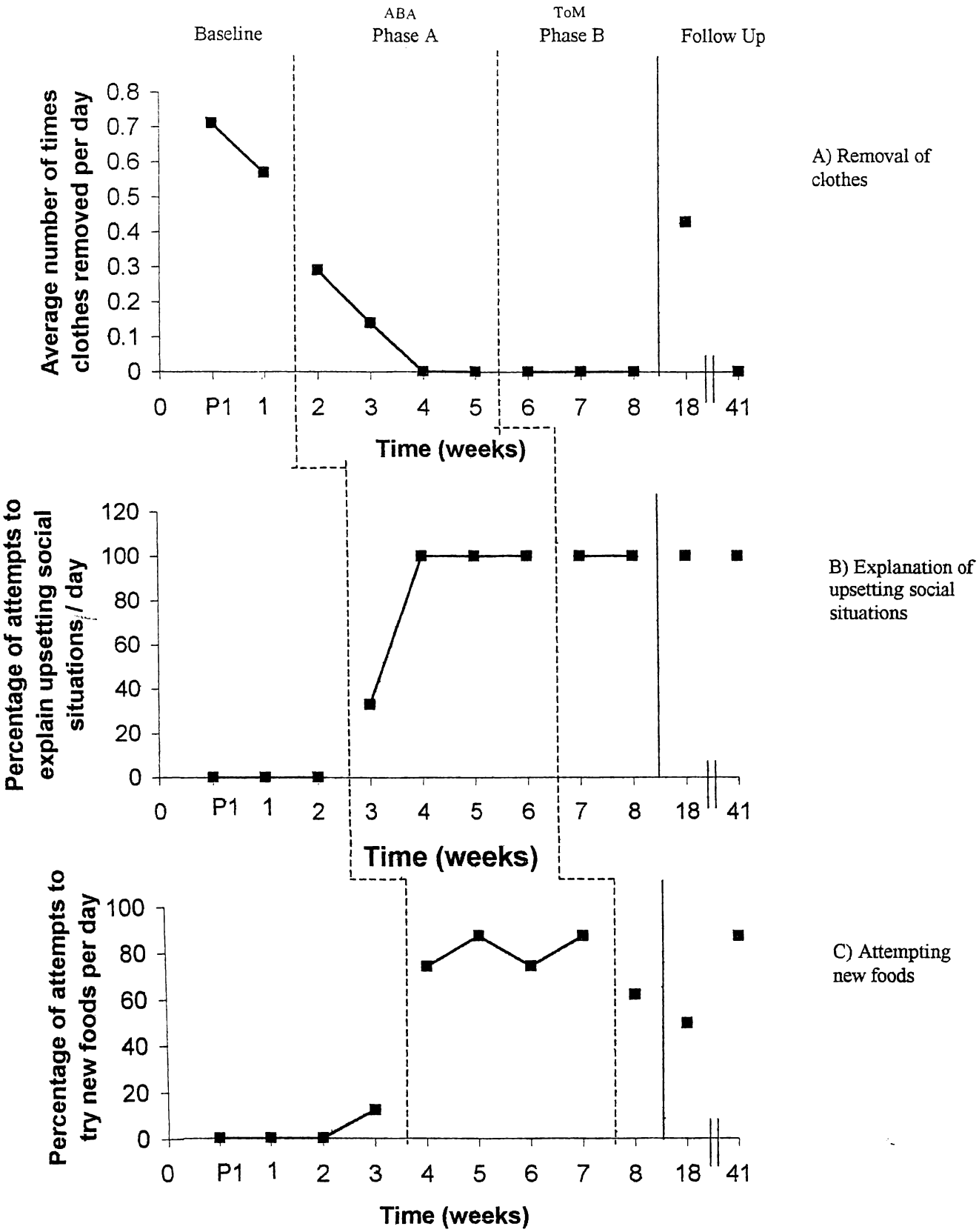


Figure 1. Comparison of two programme components over three challenging behaviours for a child with ASD – Damon.

During the programme, rewards for successful toileting were gradually removed without adverse consequences. At follow-up, the behaviour had reverted to moderate levels but Damon's mother felt that the hot seasonal weather was contributing to this behaviour. At the conclusion of the programme, Damon put his clothes back on when requested and had gained more independent bathroom behaviours. The follow-up rate of behaviour was not considered to be representative of previous baseline-type behaviours and was not expected to persist.

Behaviour 2 – Inability to communicate distress. Prior to the start of the programme, Damon was unable to react appropriately to upsetting social situations involving himself. At these times, he would not attempt to communicate verbally with his parents but instead became agitated (shouting, crying, running to room, pushing people etc). The data presented in Figure 1b show a stable nil level of appropriate responses (i.e., attempts to communicate verbally, reduced anxiety responses) to upsetting social situations during baseline. Applied behaviour analysis revealed a tangible/ problem-solving function underlying the behaviour. Damon accessed other people, particularly his parents, to solve problems/explain situations and got very agitated when they were unable to satisfy his request for understanding. However, often the other person was unsure exactly what Damon was requesting. Indeed, his mother stated at the start of this part of the programme that she wished to focus on her own ability to communicate successfully with her son. The negative outbursts were seen as attempts by Damon to communicate his frustration ("I'm not having my needs met") and perhaps escape from continued futile attempts by others to clarify the situation to his satisfaction.

The introduction of an intervention based on ABA techniques (A) resulted in a rapidly accelerating and improved trend in the percentage of times Damon attempted to explain upsetting social situations. This trend continued until ceiling levels of behaviour were reached and were maintained during the ToM phase (B) and at both short and long-term follow-up.

During the ABA phase of the programme, agitated behaviour was successfully replaced with a more appropriate form of communication. However, functional replacement of negative behaviour was insufficient to address the issues underlying the outbursts and as a result, a social understanding component was introduced using an extension of a picture system to which Damon had already been exposed. While very successful, this system was actually based on ToM techniques so while the intervention used during phase A contributed to a successful functional replacement of disruptive behaviour, the content of the intervention was not restricted to a 'pure' applied behaviour analysis approach. Subsequently, a conclusion on the effect of the intervention for this particular behaviour was not able to be reached. Further ToM techniques were introduced in the latter part of the course and ceiling behaviours remained evident throughout the programme and at follow-up.

Post-programme, Damon was observed communicating his feelings and correctly reporting on the feelings of those around him. He was able to give verbal feedback about his feelings without resorting to disruptive behaviour and generalised his new behaviours to explanations of his parent's behaviours as well! This improved communicative behaviour received favourable comment from some people outside the family. At long-term follow-up, Damon's mother reported that the school had commented favourably on Damon's ability to 'talk in context' and 'keep up with the flow of conversation'.

Behaviour 3 – Restricted food range. A restricted food range was of concern to Damon's parents for nutritional reasons. Damon refused to eat meat and vegetables and he would gag, engage in shouting or throw food if made to eat. The data presented in Figure 1c show a stable nil/negligible attempt to try new foods during baseline. Using an applied behaviour analysis approach, negative reactions to new foods were regarded as escape behaviours. During the ABA phase, various meat and vegetable products were systematically and successfully introduced and attempts to regurgitate/throw food were ignored. Data show an improved, variable trend at a high level during this phase. As food range is deliberately increased during intervention, data reflects more opportunities to engage in desired behaviour compared with

baseline opportunities. Throughout the programme, Damon tolerated a number of new foods and even initiated attempts of novel foods much to the surprise of his parents.

A slight decrease in the rate of new behaviour was noted during the ToM phase (B) and a further slight decrease was noted at follow-up. The ToM phase introduced the notion that intolerant eating habits have effects on others in the situation and on Damon himself in terms of health. At short-term follow-up, a drop in data reflected a less systematic approach to trying new foods but tolerance was still evident and the behaviour was no longer considered an issue (by Damon's mother). A long-term follow-up probe revealed a return to ceiling levels of behaviour.

Damon's mother reported improved family communication during the course of the programme and noted that Damon had become more settled and asked more questions than previously. Damon's father (who had not been part of the programme) was reportedly utilising ToM techniques in interactions with his son. Subsequent to the programme, Damon's parents independently devised two new plans to deal with other disruptive behaviours. Records produced at follow-up showed successful generalisation of new skills and favourable behavioural results.

Fern

Behaviour 1 – Interrupting conversation. A high rate of interrupting behaviour was recorded at baseline whereby Fern would disrupt the conversation of others without concern for participants or the topic of conversation. The data presented in Figure 2a show a high variable, decelerating-improving rate of interrupting behaviour at baseline which continued during the ABA phase (A) at a reduced level until floor/nil levels were reached.

An applied behaviour intervention was based on the identification of attention as the underlying function of the behaviour. Visual supports (hand signals, 'traffic lights') were used to support alternative behaviours due to the age of the child (3 years). Further visual supports were utilised during the ToM phase and behaviours were

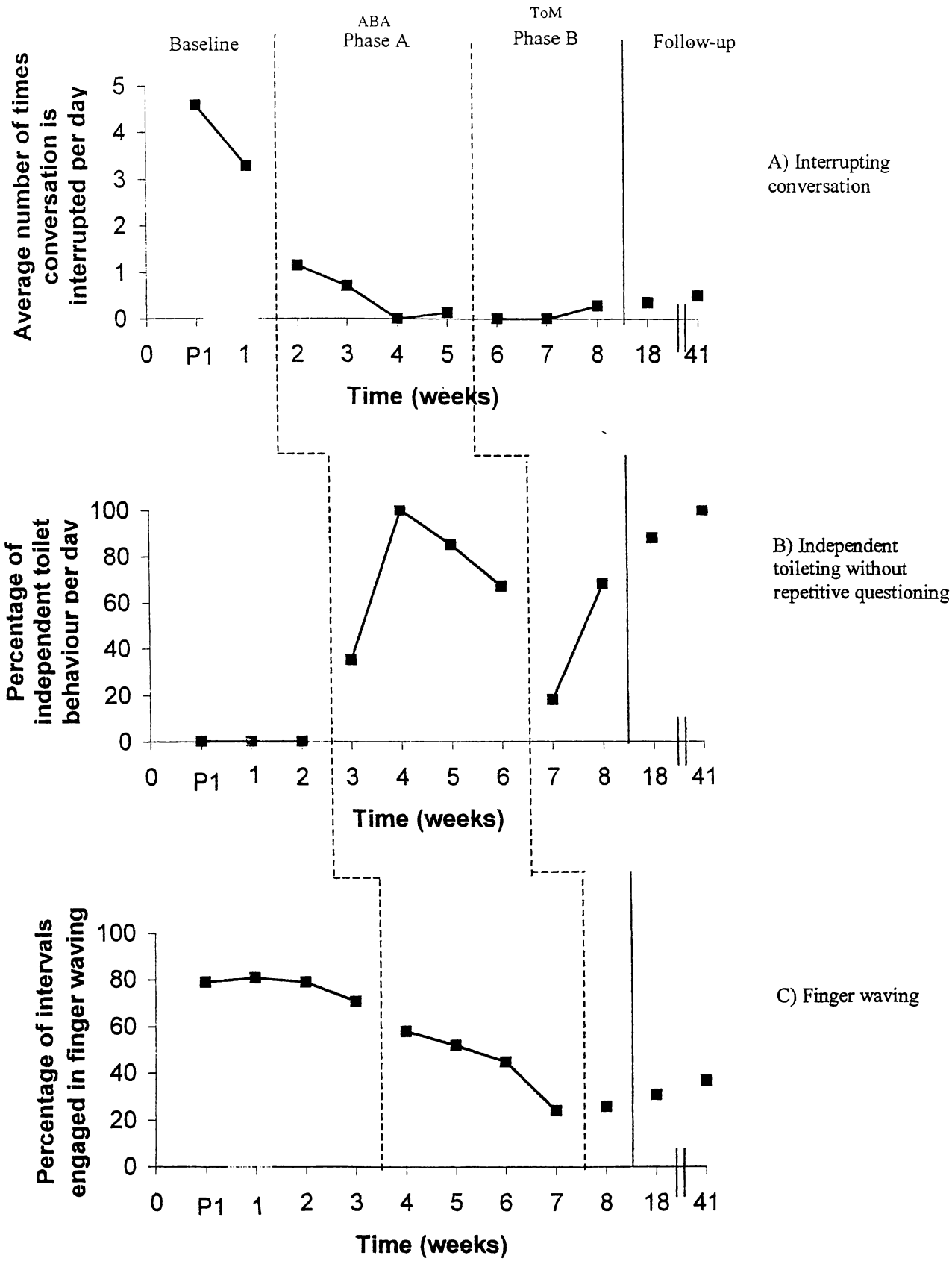


Figure 2. Comparison of two programme components over three challenging behaviours for a child with ASD – Fern.

maintained at low/negligible levels throughout the course and at follow-up. Other family members also used the visual techniques to support generalisation of behaviour to interactions between Fern and themselves and Fern and others. At follow-up, Fern's mother reported that while Fern still interrupted conversations at times, she was very good at waiting for her turn when reminded with a simple hand gesture.

Behaviour 2 – Non-independent toileting behaviour. The criteria for the second target behaviour changed prior to baseline recording in response to a request by Fern's mother to address a behavioural pattern that had developed to stressful levels: non-independent toileting behaviour. Fern had recently begun toilet-training but a pattern of behaviour had developed whereby she would repeatedly ask her mother if she could go to the toilet and if her mother would accompany her. Requests did not stop unless Fern's mum acknowledged her and toileting behaviour was not completed successfully unless her mum accompanied her to the toilet despite former independent behaviour being displayed.

Data presented in Figure 2b show a stable, nil level of independent toilet behaviour at baseline. The function underlying this behaviour was assessed as variable and a multiple functional approach (including controlling requests for attention, teaching systematic re-dressing skills and gradually increasing the mother's distance from the bathroom) were used during the ABA phase (A). Data show a steep accelerating-improving trend followed by a reversal at high levels compared with baseline. Another steep accelerating-improving trend was noted during the ToM phase of the programme. This period of changeover from applied behaviour analysis techniques to ToM intervention coincided with Fern starting kindy and holidays in an unfamiliar environment. A drop off in the level of desirable behaviour at this stage could therefore be attributed to environmental variables. Behaviours improved again upon return to the home environment and both short and long-term follow-up probes revealed a high level of independent toileting behaviour.

Behaviour 3 – Finger waving mannerism. Fern engaged in a manneristic behaviour - finger waving - which occurred at very high rates throughout the day (up to 100% of intervals probed). This behaviour consisted of flickering finger movements near the eyes or in the peripheral vision field at ear level accompanied by gross arm movement towards the body centre line. The behaviour escalated in situations of sensory stimulation and in situations where Fern was excited. Data presented in Figure 2c show a fairly stable, high level of target behaviour at baseline. Fern's mother expressed specific concerns about the social obtrusiveness of this behaviour in public.

An applied behaviour analysis approach was based on the premise that the behaviour served a tactile/motion sensory function. (Although appearing visually stimulating, the behaviour was not primarily assessed to be fulfilling a visual sensory function). Implementation of a replacement behaviour (ball-squeezing) was limited to a small percentage of the day when the target behaviour was observed to have a high probability of occurring and successful results were noted with this limited approach. During the ABA phase (A), a decelerating-improving trend was observed. The replacement behaviour was also accompanied with a verbal command, "'hands down", and finger-waving continued to decline as the verbal command eventually replaced the ball-squeezing exercise.

People outside the family unit commented favourably on the reduction of mannerisms displayed. At the end of the applied behaviour analysis phase of the programme, behaviour was occurring on average around 20% of intervals probed and behavioural changes stabilised at this level during the ToM phase. Probes over the follow-up period revealed an increase in mannerisms to an average of 37% of the intervals probed at the 41 week follow-up. This rate of behaviour was still considerably less than that observed during baseline. Fern's mother reported that Fern had been observed to occasionally check her own behaviour without being verbally reminded to put her hands down.

Piripi

Behaviour 1 – Turning TV on and off and hitting TV. Piripi's TV behaviour caused major disruption to family life as Piripi would continue to turn the TV off and on while it was being watched by others. This pattern of behaviour was prevalent at all times when the TV was on. A common chain of behaviour was Piripi banging the TV with his fist, turning it off and/or turning the sound down. Besides the escalation of disagreement with his siblings over this behaviour, there was also a real concern that Piripi would damage the TV and/or knock it over. The data presented in Figure 3a show a steep, accelerating-deteriorating trend of TV behaviour at baseline.

The function of this behaviour was not immediately clear but was assessed as being a combination of sensory/tangible/escape functions. A triple plan of action was implemented to address each function. For example, in an attempt to functionally replace the escape aspect of the disruptive behaviour, Piripi was taught to use the volume control and taught to play in his room if the TV was on and he didn't want to watch it. During the ABA phase (A), a variable, decelerating-improving trend was noted. Piripi was taught to use his room as an alternative play-place and he was observed to be going independently to his room at times. Less stress was noted by his mum (Lynn) around TV watching for all children. It was noted that Lynn also independently but intermittently restricted TV viewing periods for all the children. Behavioural records showed similar patterns of TV watching over the entire course of the programme so restricted viewing was not considered to be a significant factor in changes noted in the target behaviour.

A rise in the target behaviour was noted when the intervention for behaviour 2 was instituted and this was a particularly stressful time for Lynn (see below). However, she continued to apply intervention techniques and by week four, the banging of the TV had completely ceased and did not arise again during the course of the programme or in follow-up. Piripi's tendency to turn the appliance off or volume down also reduced to a less significant level by Lynn's report and variable low-level behaviour was observed during the ToM phase (B). Lynn noted that decreases in TV behaviour also generalised to decreases in turning the car radio and home stereo

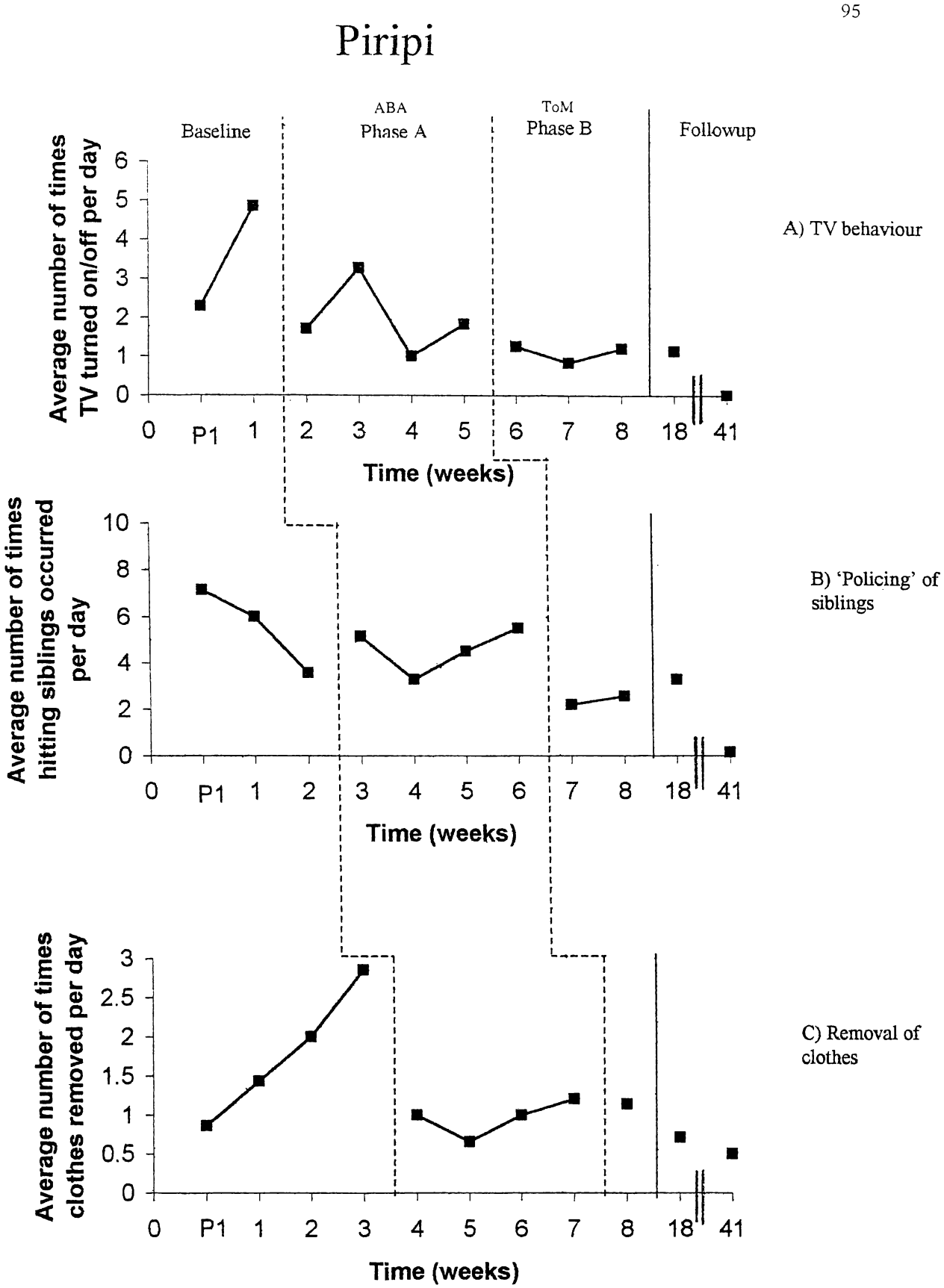


Figure 3. Comparison of two programme components over three challenging behaviours for a child with ASD – Piripi.

on/off. By the end of the programme, this behaviour was reported to be reduced and tolerable and remained so at short-term follow-up. Despite a family shift outside the Hamilton region and considerable stress experienced by the family, records at long-term follow-up revealed that this behaviour was occurring at a nil level.

Behaviour 2 – Policing and hitting siblings. Behaviour 2 was initially defined as Piripi's tendency to take discipline matters concerning his two younger siblings into his own hands without being able to apply the same 'rules' to himself. However, during the initial stages of the programme it became clear that Piripi's 'disciplining' behaviour was excessive and the target behaviour became hitting of his siblings. The data presented in Figure 3b show a decelerating-improving trend in 'policing' behaviour at baseline. However, this trend was thought to partially reflect the introduction of a variety of interventions for behaviour 1. Indeed, a lot of 'policing' behaviour revolved around TV watching.

The target behaviour became variable during the ABA phase (A) and dropped to low stable levels during the second part of the programme (phase B). During the initial stages of the applied behaviour analysis phase, Lynn found the intensity of Piripi's behaviour particularly trying and stressful. A number of other behaviours developed or increased during this period including repetitive door slamming, pulling over furniture, urinating on the floor and 'sneaky' hitting. At the same time, Piripi's father questioned the family's involvement in the programme citing behavioural increases as stressful and also questioning the cultural aspects of trying to change Piripi's behaviour, suggesting that Maori culture was perhaps more accepting of difference. Lynn noted however that Piripi's hitting behaviour was neither tolerated or accepted by his extended whanau. Moreover she had concerns about her own relationship with Piripi and was worried about her ability to cope with his physical strength and behaviours as he aged. She desired to continue the programme and the other group members were encouraging and supportive towards her and this decision.

Specific suggestions targeting current problem behaviours were addressed (e.g., specified period of time out for hitting and door slamming, helping to clean up when

urinating on the floor) and one-to-one and community support systems were put in place. Lynn continued to implement strategies as chosen and also started applying ToM techniques to all children for consistency as the youngest had begun to copy some of the disruptive behaviours displayed by his brother. She found the ToM approach to be particularly useful for enhancing Piripi's level of understanding of the effects of his behaviour on others and applied these techniques to her two younger children as well. By the end of the programme, behaviour 2 (i.e., hitting siblings) was reported to have 'changed'. It was generally less frequent and less severe according to Lynn's report. However, Lynn felt that she had 'hit a brick wall' with the behaviour as the ideal goal would be complete cessation of hitting. She felt that the youngest child's behaviour provoked outbursts from Piripi and this ongoing developmental aspect of the family was complicating resolution of the situation.

At short-term follow-up, moderate levels of this behaviour were still evident and there was considerable pressure from others in the extended family to increase the 'punishment' component of the consequences applied to Piripi for this behaviour. Lynn expressed a desire to persevere with non-aversive practices. The adjunct behaviours that had arisen previously were still occurring on occasion but were reported as 'feeble' attempts. A long-term follow-up probe at 41 weeks revealed that the target behaviour occurred once in a seven-day period. Lynn was very happy with this result and noted that while Piripi became verbally upset, he seldom hit his siblings.

Behaviour 3 – Removal of clothes. The data presented in Figure 3c show a stable accelerating-deteriorating trend in the average number of times Piripi removed his clothes inappropriately per day at baseline. Reduced but variable levels of behaviour were noted during the ABA phase (A) of the programme and these changes persisted during the ToM component (B).

During the course of the programme, a distinction between the different forms of the target behaviour were noted. Initially, Piripi removed his clothes as part of his toileting routine and failed to put them back on. The function of this behaviour was

assessed as a sensory (over-heating) issue. Lynn also correctly identified an underlying skills deficit - it had been assumed that Piripi knew how to replace his clothes when in fact, he did not. Lynn implemented a successful step-by-step plan designed to teach Piripi to replace his underclothes after toileting.

During the ToM part of the course and with an increased understanding of ASD, Lynn realised that another form of this behaviour existed. Piripi would come home from school, remove his clothes and then either bounce on the bed or snuggle beneath the covers for periods of up to half an hour. An escape or relief function was believed to underlie this form of the target behaviour and Lynn was encouraged to give Piripi a period of quiet time to himself on arrival home from school so he could 're-acquaint' himself with his environment. A low rate of behaviour was noted at follow-up and Lynn no longer felt this behaviour was problematic within the boundaries she set. At long-term follow-up, Lynn noted that Piripi still removed his clothes for toileting but now utilised routine and replaced them afterwards. He was also independently restricting which clothes he removed when stressed (top/singlet) so the behaviour was no longer considered socially inappropriate.

During the ToM part of the programme, two family tangi took place (weeks 5-7) and all target behaviours increased slightly outside the familiar home environment. In this situation, Lynn relied almost exclusively on ToM techniques with steady progress. By the time of the second tangi (week 7), Piripi's behaviour had improved and no hitting was observed at this occasion. A grandparent voiced a noted improvement in his behaviour. Mum felt more confidence in her parenting skills and also noted an increase in Piripi's verbal skills and decreased anxiety behaviours. She generalised the skills from both parts of the programme successfully to the other children and in different settings. For example, she used the ToM techniques to reduce hitting behaviour between the two younger siblings and utilised a combined applied behaviour analysis/ToM approach (non-contingent attention, provision of extra activities, pictures of facial expressions) to increase compliance at family gatherings.

At follow-up, all behaviours had decreased from baseline levels and Lynn reported Piripi to have made major positive gains in both behaviour and verbal functioning. However, accompanying family stressors meant that Lynn generally felt socially isolated in her attempts to deal with the ongoing behaviours associated with ASD. Subsequent to the first period of follow-up, the family shifted regions within New Zealand and moved into a community with extended whanau support. At long-term follow-up, Lynn reported that new behaviours (e.g., running away) had arisen due to the stress and changes inherent within a new environment. She felt that Piripi had made 'awesome progress' on the target behaviours and reported that while the approaches took time, the results were worth the effort of 'hanging in there'. Moreover she noted that positive behaviour changes had been maintained over a long term and she felt confident about attempting to address other, 'new' behaviours.

Hugh

Behaviour 1 – Tantrums and anger. 'Tantrum' behaviour consisted of shouting, directing verbal abuse at family members, running from the room, slamming doors, hiding and refusing to speak. This pattern of behaviour could persist over a 24 hour period from a single incident. While the data presented in Figure 4a show a decelerating-improving trend in tantrum behaviour at baseline, Hugh's mother reported variability in Hugh's behaviour (which would have benefited from an extended baseline measurement period). Applied behaviour analysis revealed a joint tangible/escape function underlying Hugh's 'tantrum' behaviour and Hugh was initially taught to replace the target behaviour with a verbal request/ statement. During the applied behaviour analysis phase (A), a change in level was noted and the deceleration-improving trend continued to zero levels. A number of behavioural improvements were reported by Hugh's mother; Hugh became more settled in general interactions with his brother, episodes of anger reactions were reduced in duration, and Hugh's tolerance increased. For example, incidents which would have caused a problem prior to the programme, no longer produced a reaction. His mother also felt she could talk to Hugh about his behaviour without him 'storming off' or 'sulking'.

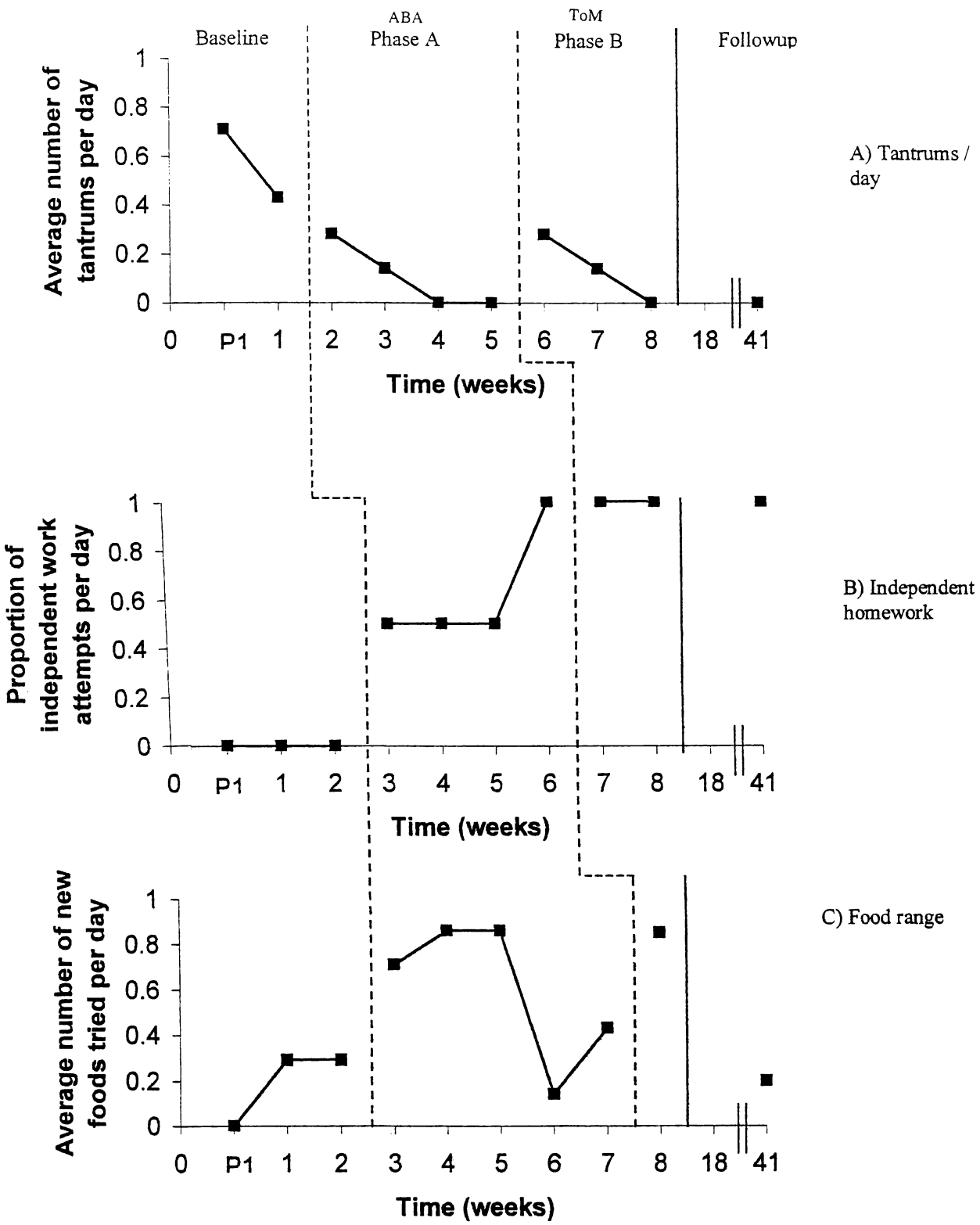


Figure 4. Comparison of two programme components over three challenging behaviours for a child with ASD – Hugh.

During the ToM intervention phase (B), nil behaviours were not initially maintained, but subsequently a further decelerating-improving trend was noted to floor levels. A slight increase in disruptive behaviour (two incidents in one week) at the beginning of phase B coincided with his mother reporting that her own relaxed attitude towards Hugh's behaviour lead her to try joking/teasing him which Hugh did not respond well to. In the same week, an incident at school was reported which indicated generalisation of Hugh's skills in successfully dealing with a difficult social situation. By the end of the programme, anger and shouting incidents were nil and his mother reported noticeable increases in Hugh's level of communication and responsibility. Due to family travel, no short-term follow-up data was available, however long-term follow-up data revealed nil behaviour was maintained.

Behaviour 2 – Non-independent in homework. Hugh made no attempt to work independently on his school homework tasks during baseline (Figure 4b). Furthermore, when presented with school tasks, Hugh refused to allow his mother to assist/correct him and would not seek help. His mother initially viewed this behaviour as an inherent and undesirable characteristic and was frustrated by Hugh's lack of communication around tasks for which he obviously required assistance. However, during ABA phase it was proposed that the function underlying Hugh's behaviour was avoidance/escape because the work being sent home from school was too difficult. In order to test this hypothesis, an easier set of tasks was devised and Hugh willingly engaged in these. A meeting with the class teacher and his mother lead to clarification of expectations and a new homework sheet was introduced. Figure 4b shows a stable then accelerating-improving trend to goal behaviour during the applied behaviour analysis phase (A). Gains were maintained throughout the remainder of the programme and at long-term follow-up.

In this particular case example, it was difficult to differentiate the effect of the two phases of the programme. ABA (with a functional emphasis) involves identification of the function of a particular target behaviour and replacement with a functionally-equivalent behaviour. This process can occur without reference to an underlying 'cause' and behaviour change is purported to occur whether or not one has access to

such a 'cause'. However, in this case, it was not desirable that Hugh should be taught to simply replace an avoidant/escape response with a verbal indication of his need for help without addressing the underlying maintaining variable - the level of difficulty of the homework tasks. Moreover, while level of homework difficulty is not restricted to a consideration of ASD issues, an analysis of environmental contingencies is part of the ToM approach. As such, while the positive outcome in terms of behaviour change occurred during the applied behaviour analysis phase of the programme, the type of intervention chosen (in order to avoid with-holding necessary educational changes) may have confounded the ability to attribute success to one component of the programme over the other.

Behaviour 3 – Restricted food range. Behaviour 3 consisted of a restricted food-range which was in effect an aversive response to attempts to try new foods. Data presented in Figure 4c show a variable, low-level, accelerating-improving trend towards trying new foods during baseline. This was followed by a variable, decelerating-deteriorating trend during the ABA phase (A). Intervention (systematic introduction of new foods in small portions, shared food preparation, rewards for attempting new foods) for behaviour 3 (restricted food range) was started independently by mum a week before intended and while the results were variable, they were also generally positive. As noted previously (Damon, behaviour 3), due to the deliberate introduction of new foods, data reflects more opportunities to engage in desired behaviour compared with baseline. A probe during the ToM intervention phase (B) showed a high level of goal behaviour compared with baseline and by the end of the programme, Hugh's mum reported that Hugh was consistently trying new foods as they were presented and occasionally requesting new items. At follow-up, Hugh was reported to try new foods as they were presented and this behaviour was no longer considered problematic.

Flynn

Behaviour 1 – Inflexible demanding of mother's time. 'Demand/timing' consisted of Flynn repeatedly demanding his mother's attention and time. If not responded to immediately, Flynn reacted with shouting, verbal aggression, throwing

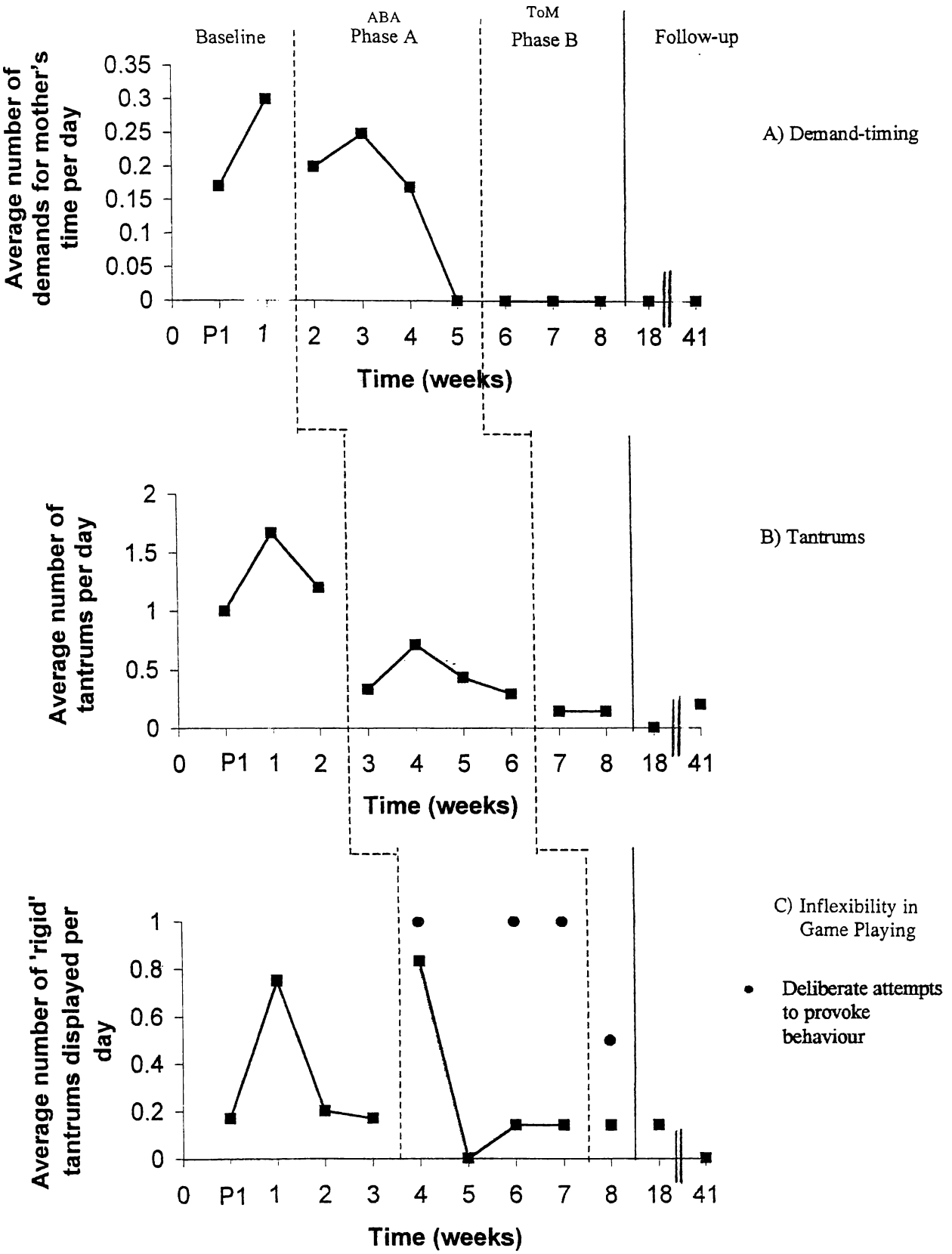


Figure 5. Comparison of two programme components over three challenging behaviours for a child with ASD – Flynn.

objects and slamming doors. The data presented in Figure 5a show an accelerating-deteriorating trend in the target behaviour at baseline. The function underlying the behaviour was assessed as tangible. As Flynn already verbally requested what he wanted, the issue was really more one of his reaction when told that he could not have what he wanted *right now.* In an attempt to remove the immediacy of the expected response, intervention during the ABA phase (A), was directed at teaching Flynn to wait a short time before expecting a response. A reversal in the trend of the target behaviour occurred during this phase to nil behaviour levels. Nil behaviour was maintained during both the ToM phase (B) and at both short and long-term follow-up. Flynn was also observed to have re-directed himself to another task when he was dissatisfied with the time interval between a request and expected response.

Behaviour 2 - Tantrums. The data presented in Figure 5b show a variable pattern of tantrum behaviour following an accelerating-deteriorating trend at baseline. Tantrum behaviour consisted of similar behaviours to that noted above (behaviour 1) but without the setting event of demands for his mother's time. Indeed, these two behaviours were often combined and the underlying function of both was assessed as tangible. As such, the variability noted in baseline may be partially explained by the implementation of intervention for behaviour 1. A similar intervention and consistent approach by his mother during the ABA phase (A) with behaviour 2, resulted in a decelerating-improving trend in the target behaviour over the course of the programme. A stable, low level pattern of behaviour was noted during the ToM phase of the programme and nil/negligible levels of behaviour were maintained at follow-up.

Behaviour 3 – Inflexibility in game-playing. Game playing was a common and enjoyed past-time in Flynn's family, however Flynn's rigid and inflexible behaviour was particularly problematic in this context. If prevented from applying his own rules (usually in an attempt to win), Flynn would shout, physically hit others and throw the game over. The data presented in Figure 5c show variability of behaviour but no obvious trend during baseline. Low levels of behaviour reflect a tendency by other family members to avoid situations that could provoke target behaviour.

Variable functions of tangible and escape were assessed as underlying these behaviours. During the ABA phase (A), the target behaviour was deliberately provoked in order to produce optimal interactions in which to shape desirable behaviour. In practice, this consisted of his mother deliberately engaging Flynn in a board game with clear rules. Flynn was encouraged to verbalise his frustration as it occurred but continuation of the game was contingent upon adhering to the correct set of rules. An initial high level of behaviour was observed followed by a decelerating-improving trend to stable/negligible levels. A probe during the ToM intervention phase (B) showed maintenance of intervention gains while probes at both short and long-term follow-up revealed nil target behaviour in this context. In other words, Flynn was able to participate in games with others using universal rules. The quality of Flynn's interactions in a 'controlled game-playing' setting improved and he no longer destroyed games for others. While rigid behaviours persevered in some other settings, his mother reported that family members had successfully generalised ToM techniques to introduce change and Flynn was observed to tolerate and in some circumstances, instigate alternative approaches to tasks.

Over the course of the programme, both behaviour 1 and 2 reportedly became less severe and of less duration. Flynn was also observed to be more settled and happier in his approach to school. He became more communicative and rather than 'acting out', began to ask more questions. Flynn's mother found herself taking more time to answer his queries and found the ToM information to have produced the most change for her own behaviour. She had introduced the skills to other people within the family and had helped teachers implement the same skills in the school setting. Moreover, she was observed generalising the skills learnt to other behaviours to prevent them becoming problematic.

Summary of Behaviour Changes for Group One

Fifteen behaviours were observed during the course of the programme for Group One (see Table 3). Over this period of time, 14/15 (93.3%) of target behaviours changed in a positive direction (i.e., positive trend or level using criteria for significant change from Tawney & Gast, 1984). No behaviours changed in a negative direction and only one (6.7 %) showed no clear evidence of change. Qualitatively, this latter behaviour did change in a positive direction under specific conditions (see Flynn, behaviour 3); but the change was not great in comparison with baseline trend/level. All target behaviours were reported to have changed in a positive direction by parent participants. In cases where change was not clearly observed in terms of frequency, positive change was often noted in reductions in intensity or duration of the target behaviour. Parent participants reported that 11/15 (73%) behaviours were no longer evident or were no longer considered problematic at the conclusion of the programme. Short-term follow-up data were available for four parent-participants. Results showed that these gains were maintained over a ten-week period. Long-term data were collated for all participants. Results showed all gains were maintained or improved over a seven-month period.

Table 3

Summary of the Direction of Behaviour Changes over the Course of the Programme for Group One Participants

	Socialisation Behaviour 1	Communication Behaviour 2	Restricted/rigid Behaviour 3
Damon	+	+	+
Fern	+	+	+
Piripi	+	+	+
Hugh	+	+	+
Flynn	+	+	NC

Note. + = positive change, NC = no change.

The target behaviours per child were generally chosen on the basis of the triad of difficulties inherent within the area of ASD ie, socialisation, communication and restricted range of interests/rigidity. Within Group One participants, results show

100% (5/5) of the socialisation and communication behaviours targeted during the programme changed in a positive direction to non-problematic levels. One communication behaviour changed in a positive direction but remained at moderate levels a short-term follow-up. Nil levels of behaviour were reached at long-term follow-up. Eighty percent (4/5) of the restricted/rigid behaviours targeted also changed in a positive direction over the course of the programme although none of these behaviours reached ceiling/floor levels. However, all remained improved at follow-up compared with baseline. One restricted/rigid behaviour showed no clear change over the course of the programme.

Summary of Course Components for Group One

As noted above, positive behavioural changes were seen in 93% of behaviours targeted for intervention. However, an area of interest in this study was the investigation of possible differences between the two course components (applied behaviour analysis and ToM) on behaviour changes.

The effect of the applied behaviour analysis approach was more evident in this group as it was the first part of the programme and was consistently applied for a four week period over each behaviour. As the length of baseline varied according to the multiple baseline format, the ToM phase also varied in length over the course of the nine week programme. Some results were less robust due to fewer average weekly data points. Also, a prior competence on the part of the parent participants in terms of applied behaviour analysis techniques was assumed at the time of introducing the second set of techniques (ToM). In some cases, target behaviours had reached ceiling/floor levels *before* the implementation of the ToM phase. This outcome was reversed in discussions of Group Two data. Final conclusions about the efficacy of both components are drawn after completion of both sets of group data.

Table 4

Summary of Data Trend and Level for Applied Behaviour Analysis (ABA) and ToM Phases of the Programme for each Behaviour for Group One Participants

Behaviour	ABA (phase A)		ToM (phase B) cf. ABA	
	Trend	Level	Trend	Level
Damon 1	NC	++	Maintained at floor level	
2	+*	++*	*Maintained at ceiling level	
3	NC	+	Maintained at moderate level	
Fern 1	NC	++	Maintained at neg level	
2	+	+	Repeat pattern to fn. levels	
3	NC	+	Maintained change	
Piripi 1	+	+	Maintained result, ↑ stability	
2	-	NC	NC	+
3	NC	+	Maintained change	
Hugh 1	NC	++	Repeat pattern to floor again	
2	+*	++*	*Maintained at ceiling	
3	-	+	Positive high-level probe	
Flynn 1	+	++	Maintained at floor level	
2	+	+	Maintained change	
3	NC	NC	NC - probe data	

Note. ++ = positive change to stable floor/ceiling levels, + = positive direction change, - = negative direction change, NC = no change in direction, * phases not clearly separated - see individual data description for explanation.

Data trends and levels were analysed to ascertain the relative effects of the two phases of the programme (refer Table 4). Particular attention was paid to the ABA component of the course. During this first phase of the course, 6/15 (40%) target behaviours changed in a positive trend and level compared with baseline, however two of these behaviours (as denoted by an asterisk - Damon, behaviour 2 – explanation of upsetting social situations and Hugh, behaviour 2 – lack of independent homework) were complicated by cross-over with ToM technique. A further 6/15 behaviours showed a positive change in level compared with baseline but showed no change in trend. Removing the two behaviours for which the interventions were compromised, 10/13 behaviours (77%) changed in a positive direction during the ABA phase of the programme. One behaviour showed no change over the ABA part of the course (or during the remainder of the course, i.e., Flynn – behaviour 3: inflexibility in game playing). The final two behaviours showed a

negative/deteriorating trend during the ABA phase compared with baseline. Of these, one showed a positive change in level while the other did not. These results indicate that the latter behaviour (Piripi, behaviour 2: hitting/policing siblings) worsened over the period of applied behaviour analysis intervention (see discussion for this case). A positive change in level of this behaviour was noted during the ToM phase. Of the ten behaviours that changed in a positive direction, four reached ceiling/floor levels and a further three behaviours reached floor/ceiling levels during this phase with variability.

The last column of the table shows the effects of behaviour during the administration of the second course component (ToM). Changes in behaviours were analysed with reference to behaviour change recorded at the completion of the first component (i.e., at the end of the ABA component). For example, during the ToM phase, Fern-behaviour 2 (lack of independent toileting), shows a repeat of the patterns (positive change in trend, positive change in level) shown during the ABA component. In other words, this behaviour was observed to return to near-baseline levels during the ToM phase (i.e., gains during the ABA phase were not initially maintained) but then followed positive changes to the same levels achieved during the applied behaviour analysis phase. In another example, during the ToM phase, Flynn-behaviour 1 (tantrums/demand timing), shows that the behavioural gains made during the first half of the programme were maintained at floor levels.

Of the 10/13 positive changes noted during the ABA, eight of these gains were maintained at ABA phase levels during the ToM phase. The remaining two behaviours showed variability during ToM but both showed a repeat of the patterns observed in phase A, to return to similar intervention levels. One behaviour (Flynn, behaviour 3: inflexibility in game playing) showed no significant change in trend or level during any part of the course. Two behaviours showed a negative trend during ABA intervention (Piripi, behaviour 2: hitting/policing siblings and Hugh, behaviour 3: restricted food range). One behaviour (Piripi, behaviour 2) showed an improvement in level during the ToM phase only. The other (Hugh, behaviour 3) showed a corresponding increase in level during ABA and this level was maintained during the ToM phase (B).

Comparing the results across the three behaviour classes in the triad of ASD behaviours, demonstrated that 100% (5/5) of the targeted socialisation behaviours showed positive changes over the ABA phase of the course (4/5 of these behaviours reached floor/ceiling levels). All these changes were maintained during the ToM phase. Two of the targeted communication behaviours were compromised (due to confounding of the applied behaviour analysis and ToM component) and removed from analyses. Of the remainder, two showed positive changes that were maintained or repeated during ToM, and the other showed a deterioration during the ABA phase and a corresponding positive level change during ToM. With reference to the restricted/rigid behaviours, 4/5 of the targeted behaviours showed improvement during the ABA phase of the programme and gains were maintained or at least repeated during the ToM phase. The remaining behaviour showed no clear change over the course of the programme.

Data Description - Group Two

In this section, the data from participants in Group Two will be examined. For this group, the programme consisted of a variable period of baseline preceded by two weeks of pre-programme baseline data (P1 & P2). The programme commenced at week 1 with the ToM component and the ABA component followed at week 5. As with Group One, follow-up probes were conducted at ten weeks and seven months after the conclusion of the programme.

Kyle

Behaviour 1 – Anger behaviour. Kyle's mother was concerned about her sons' 'attitude' . When angered, Kyle would respond with verbal aggression/shouting, 'storming off'and at times, running away. He was generally non-responsive or hostile to attempts by others to remedy the situation and the duration of the behaviours was often excessive. Data presented in Figure 6a show an accelerating-deteriorating trend in the target behaviour over baseline. During the ToM intervention phase (B), in which diagrams and picture stories were used to show the effect of Kyle's behaviour

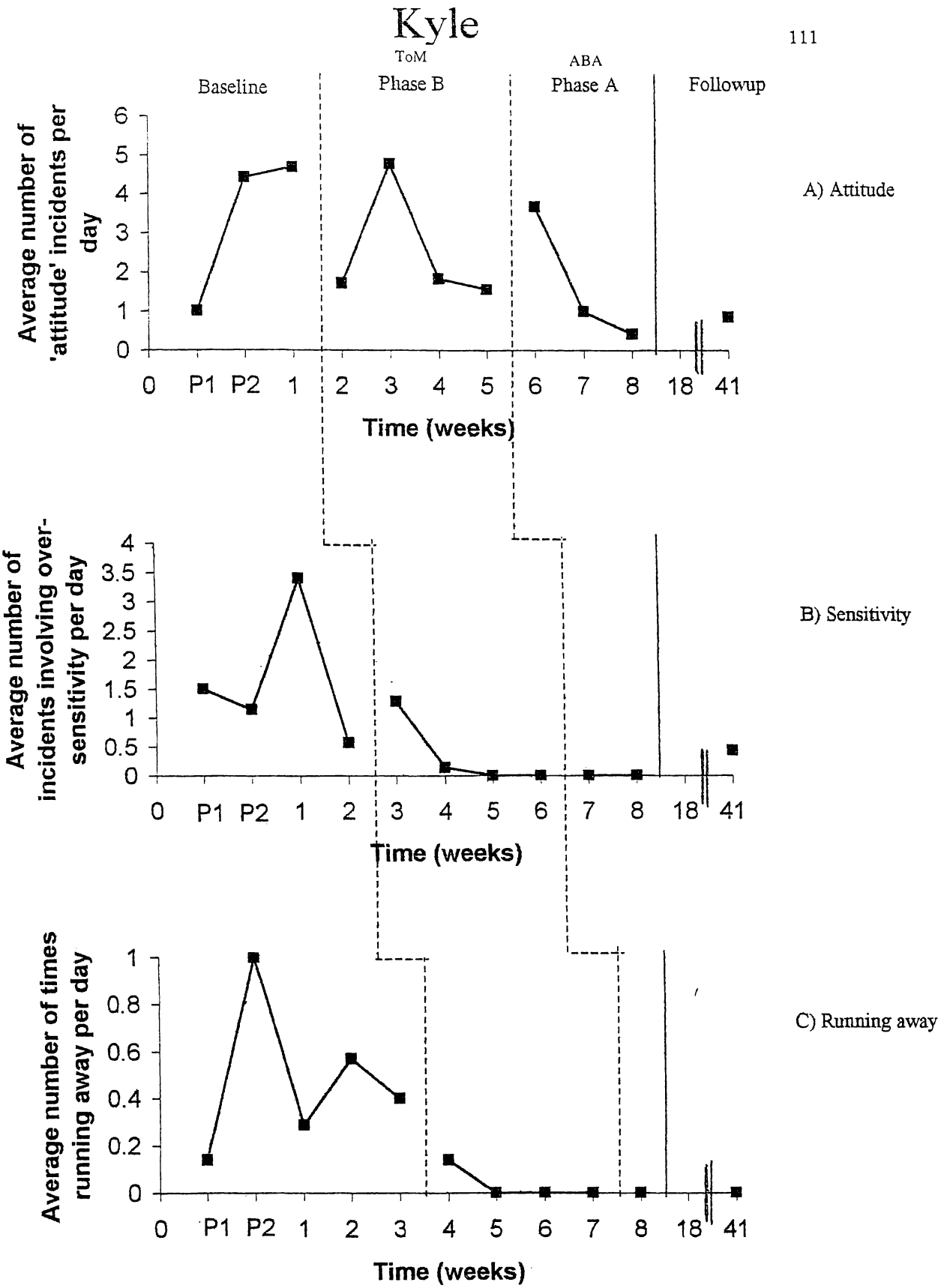


Figure 6. Comparison of two programme components over three challenging behaviours for a child with ASD – Kyle.

on other family members, behaviour was variable with a reversal of the baseline trend noted. One peak in the data coincided with Kyle being cared for by an unfamiliar caregiver. As the data are presented in an average form, this peak actually consisted of two days of poor behaviour. During the ABA phase (A), behaviour was again variable and a reversal of the baseline trend was initially noted as in the previous intervention phase. Kyle's mother reported that the peak during this phase coincided with Kyle being removed from medication to control anxiety. However during the entire intervention procedure, medication was utilised with variable behaviour noted, so the conclusions drawn from this are to be taken with caution. Short-term follow-up data were unavailable due to family circumstances. Long-term follow-up results show a low rate of behaviour (less than one incident per day).

In summary, 'attitude' behaviour showed variable results during the course of the programme with both intervention phases showing reversed trends and positive level changes compared with baseline. Lower levels of behaviour were also generally evident. At the conclusion of the programme, Kyle's mother noted that the severity of Kyle's anger behaviours had reduced. Instead of 'storming off' and slamming doors, he would remain in the situation and verbalise his feelings. Moreover, his mother reported that her own ability to communicate effectively with her son had led to successful resolution of a range of other potentially problematic behaviours and improved the quality of their relationship.

Behaviour 2 – Over-reaction to sibling interactions. The second target behaviour was similar in topography to that noted for behaviour 1. However, whereas the first behaviour was an anger response, Kyle's mother had identified the setting event for the second behaviour to be either a suggestion or mis-interpretation of a non-provoking verbal comment made by his brother. Kyle's mother referred to this behaviour as an extreme 'sensitivity' response to comments made by others and often it would result in crying, hiding in bedroom or escalate into anger behaviour as above. This cross-over of response could account for the drop seen in the baseline

data of behaviour 2 when intervention began for behaviour 1 (i.e., generalisation, Figure 6b).

Behaviour 2 data show a variable baseline with an initial accelerating-deteriorating trend followed by a steep reversal. During the ToM intervention phase (B), behaviour showed a decelerating-improving trend to a nil level which was maintained throughout the rest of the programme. A long-term follow-up probe revealed a low rate of behaviour was maintained.

Behaviour 3 – Running away. Kyle's behaviour of running away when angered or distressed was of serious concern to his mother for safety reasons. Kyle was seven years old and lived near a busy rural intersection. He would leave the property and would not respond to verbal calls to locate him. The data presented in Figure 6c show a variable baseline pattern with an initial high rate of behaviour followed by a decelerating-improving trend in the average number of times Kyle ran away per day. However, despite the apparent low rate of behaviours, baseline figures still represent occurrences ranging from in excess of one incident per day to one incident per three days, which was unacceptable in terms of personal safety. During the ToM intervention phase (B), low levels of behaviour declined to nil levels which were maintained throughout the rest of the programme and at long-term follow-up.

Over the course of the programme, positive behavioural outcomes were experienced using ToM material and this became the family's chosen mode of behavioural intervention. In practice, Kyle's mother would use visual pictures to illustrate the effect of his behaviour on others and to encourage Kyle to identify the feelings and emotions underlying problematic behaviour. Strategies were then developed with Kyle (again using visual supports) to enhance his understanding of expected behaviour should he experience similar feelings in the future. A situation of generalisation was noted when his mother applied ToM techniques to an anxiety problem which developed over bedtime behaviour. In this situation, his mother successfully helped Kyle to identify what would make him feel less anxious and help him sleep. Towards the end of the course, a new behaviour developed whereby Kyle

would toss cushions and self-stimulate (body rock). His mother attributed this to high anxiety levels due to bedtime fears. Kyle responded positively to instruction to pick the cushions up, without an anger response and his mother did not feel this behaviour was problematic. Kyle's father was also observed to successfully utilise ToM techniques in an interaction with his son. For example, following an outburst (anger, 'storming off') by Kyle, his father sat down and used the same visual support techniques to re-visit the situation to demonstrate what was intended, what actually happened, the 'mis-interpretation' that occurred and future expectations.

At follow-up, Kyle's mother reported that Kyle appeared to be much less anxious. She felt that by using ToM techniques, she was able to communicate with him and check his understanding before he became upset or aggressive. As a result, she felt that she was able to meet his needs more often and he was therefore less anxious and his behaviour less problematic. At the conclusion of the programme, his mother reported that Kyle was able to state how he was feeling about a particular unpleasant situation without resorting to disruptive behaviour or running away.

A number of stressful events occurred in Kyle's family over the course of the programme and some records were missed during the last part of the programme. Due to a major family disruption, no short-term follow-up data were collected. However, long-term follow-up data were available.

Bryan

Behaviour 1 – Lack of morning routine and non-compliance. The period prior to school in the mornings was extremely stressful for Bryan's mother. A number of tasks had to be performed in a short period of time, however, Bryan would not follow instruction or time limits. Instead, he would continue with his current task without appearing to have heard the instruction. On occasion when he did appear to follow an instruction, he would be found doing something else with no apparent recollection of the original task required. He showed no appreciation of the need to perform certain functions (e.g., dressing) and would often have to be chased or physically led to the

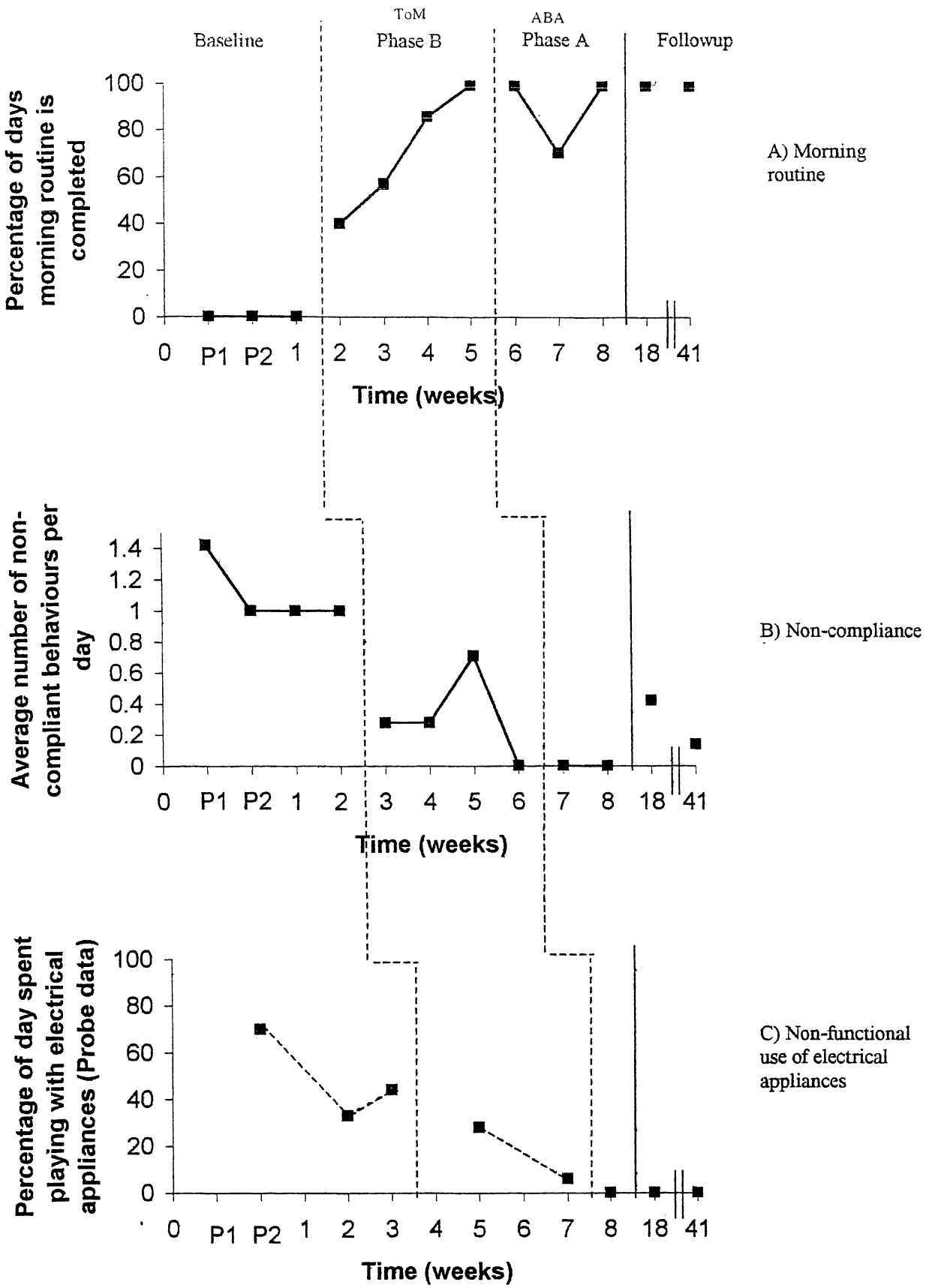


Figure 7. Comparison of two programme components over three challenging behaviours for a child with ASD –Bryan.

car. The data presented in Figure 7a show a nil and stable baseline of desirable 'morning' behaviours.

During the ToM intervention phase (B), Bryan's mother devised an extension of a card system that Bryan was already familiar with, to visually outline required morning tasks. In addition, she visually depicted the effect of Bryan's non-compliant behaviour on herself. Much to her surprise, Bryan paid attention to her drawings. In the first week of intervention, he laughed at attempts to visually depict the effects of his behaviour on others but after a few attempts (including his older sister also using visual depictions of behaviour), his mother reported that she felt some understanding was forming. The data show an accelerating-improving trend in 'morning' behaviours which reached a ceiling level during the ToM phase. High levels of behaviour were maintained during the ABA phase (A). One slight decrease was noted when visual support methods were not maintained (week 7). Upon reintroduction of these supports, behaviour returned to ceiling levels. At both short and long-term follow-up, no visual supports were being used and behaviours were maintained at a ceiling level.

Behaviour 2 – Non-compliance and tantrum to instructions. Non-compliant behaviour consisted of Bryan doing something he was specifically requested not to do or failing to follow verbal guidelines. Moreover, when remonstrated, Bryan often acted inappropriately - laughing, teasing, making faces and so on. The data presented in Figure 7b show a stable high level of non-compliance during baseline. During the ToM intervention phase (B), behaviours occurred at a variable but low level compared with baseline. An initial accelerating-deteriorating trend reversed to nil levels that were maintained over the ABA phase (A). The peak shown during week 5 related to five separate incidents of 'mischievous' behaviour as opposed to 'deliberate non-compliance' as reported by Bryan's mother. However, these incidents were recorded because the accompanying lack of understanding as shown by Bryan's responses to attempts by mum to address the behaviour, made the behaviour problematic. A short-term follow-up probe indicated that some level of problematic behaviour had returned but this was occurring at a reduced rate compared with

baseline and was no longer considered problematic. At long-term follow-up, non-compliance behaviours were occurring at negligible levels.

Behaviour 3 – Obsession with electrical appliances. Bryan sought out electrical appliances in all settings and spent the majority of his free-time at home plugging in or carting appliances around. He would engage himself in activities with these appliances to the exclusion of other activities. The majority of this activity was considered harmless and his parents specifically expressed that they did not wish to remove an obvious source of enjoyment from Bryan. Nevertheless, incidents of inappropriate use and/or inadvertent dangerous use had been a cause of concern to others in the house. Moreover, the constant handling of appliances had resulted in increased incidents of breakage and there was considerable inconvenience to the rest of the family of having to work around the various set-up arrangements.

Behaviour 3 data was probed over the course of the programme (Figure 7c). During baseline, obsessional electrical appliance behaviour occurred in 33-70% of the periods probed. Rates of target behaviour during the probe periods are under-rated as appliance use was only recorded while Bryan was at home and/or had access to appliances. During the ToM intervention phase (B), behaviour was observed at a reduced level (between 6-28%). In this part of the course, Bryan's mother focused on two features of Bryan's behaviour – the clutter and inconvenience caused by excess appliance arrangements and the non-functional use of appliances. She taught Bryan the effect (on herself) of having to work around the appliances using social pictures and used visual representations to identify where each appliance should be placed/stored. She also began teaching Bryan the correct use of various appliances.

A floor level of target behaviour was reached before implementation of ABA interventions (phase A). As there was no behaviour to work on during this phase, no applied behaviour analysis intervention took place. Appliance behaviour was still occurring at short-term follow-up but behaviour was mostly functional and no longer obstructive, inconvenient or problematic. At long-term follow-up, Bryan was reported to have engaged in electrical appliance behaviour for a total of 5 minutes in one day

and independently chose interactive or solitary play activities in preference to electrical appliance activity.

The successful resolution of target behaviours 1 and 2 and the negligible rate of behaviour 3 noted during the ToM intervention phase (B) meant that ceiling or floor effects were effectively produced before the ABA phase (A) was introduced. However, a consideration of applied behaviour analysis techniques led to an increase in the range of approaches Bryan's parents used for target behaviours. For example, in order to replace the identified function of escape from anxiety, Bryan's parents intended to use a visual choice board to offer alternative activities to supplement electrical appliance behaviour and identified an appropriate toy that involved elements of electrical appliances e.g., the ability to be plugged in.

Bryan's mother had initially verbalised scepticism towards the effectiveness of ToM techniques before implementation, especially with regards to the high rates of obsessional behaviour noted for Bryan. Subsequently, she was very surprised about the results achieved during this phase. Following success with the techniques (visual support of explanations of behavioural expectations, full explanation of task and effects of problem behaviour) learnt during the ToM part of the programme, Bryan's mother generalised the techniques to a new situation to prepare Bryan for a trip to the dentist. The success of this approach was such that Bryan's father took a particular interest in the techniques and also began applying them. By week 5, Bryan was observed utilising the same techniques to communicate his feelings to other family members. Bryan's sister also successfully utilised the techniques to explain social rules and understanding to Bryan with respect to interactions between the two siblings and the family reported satisfaction with progress noted.

Eliam

Behaviour 1 – Non-compliance. When asked to do something he didn't wish to do, Eliam would often become angry (shouting, crying, stamping off to his room) and refuse to comply with instructions. The data presented in Figure 8a show a moderate, stable pattern of behaviour during baseline. A drop in the rate of behaviour

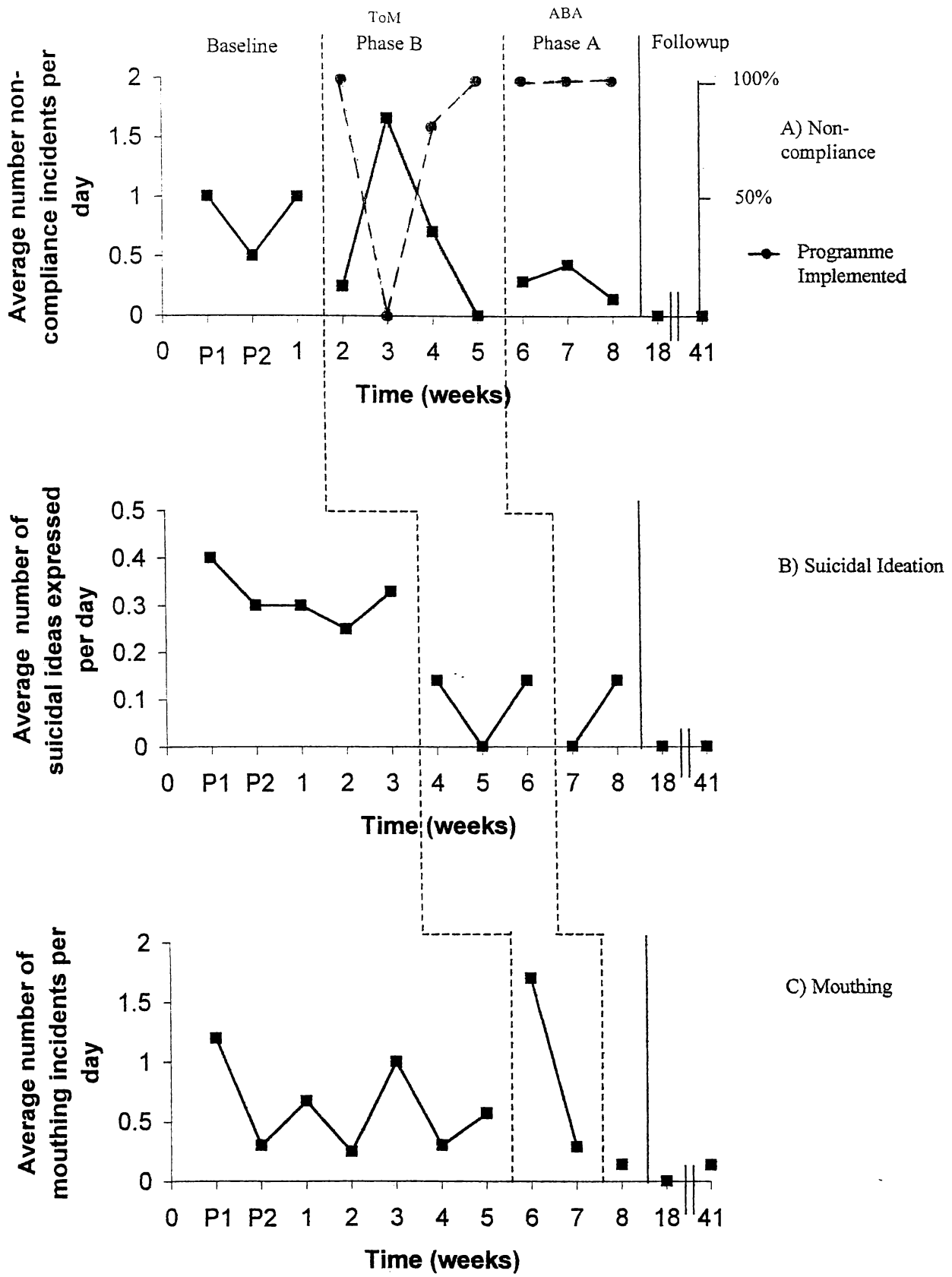


Figure 8. Comparison of two programme components over three challenging behaviours for a child with ASD – Eliam.

during this period coincided with an extended period of illness (P2) however, high rates of behaviour were considered a more accurate reflection of the rate of occurrence of behaviour by other family members. During the ToM intervention phase (B), the data showed variation around a general decelerating-improving trend. Initially, the behaviour was observed to follow an increasing trend which then reversed to nil levels. However, a peak in non-compliant/anger behaviour was apparent over a period of time during which Eliam's mother was away from the home and no intervention steps were carried out by other family members (refer Figure 8a). An inverse relationship was noted between programme implementation and target behaviour, i.e., high rates of implementation of planned intervention techniques coincided with low/nil behaviours recorded, while periods of non-use of techniques or incomplete use coincided with higher rates of behaviour. During the ABA phase (A), the implementation of intervention techniques was consistently high and the target behaviour occurred at a variable and low level. Short and long-term follow-up data showed a nil level of behaviour.

Reductions were observed in non-compliant and anger behaviours during the course of the programme. Both intervention phases showed variable but low rates of behaviour when intervention techniques were applied. Basement/nil behaviour was recorded during the ToM phase and again at follow-up. By week 7, other family members reported reductions in the intensity and severity of Elaim's anger behaviour. Moreover, anger/tantrums were less frequent and were successfully truncated as opposed to being consistent or having the previous outcome.

Behaviour 2 – Suicidal thoughts and ideation. Suicidal thoughts/ideation consisted of Eliam expressing a desire to end his life accompanied by crying and distressed behaviour. Frequent verbalisations (one per two to three days) of suicide and how others/himself would be 'better off' caused considerable alarm to his parents who would commonly refute these ideas and comfort him. The data presented in Figure 8b show that these behaviours were occurring at a fairly high and consistent level at baseline and were following a slightly decelerating-improving trend. Because of the nature of this particular behaviour, further assessment was undertaken before

continuation of the programme plan. Initially Eliam's mother spent a considerable portion of time attempting to uncover 'causes' underlying this behaviour (and also behaviour 1). However an analysis of the social understanding contributing to the target behaviour provided a focus for ToM-based intervention. For example, in one case the behaviour was preceded by Eliam's father leaving for a trip to town without Eliam but instead taking one of his siblings. This was actually a case of misunderstanding as his father was not aware that Eliam wished to go, but Eliam reacted with crying and verbalising that he would be 'better off dead' and so on. In this case, ToM techniques involved a visual depiction of the scenario as it happened and the understanding of each person involved i.e., dad did not *know* that Eliam wished to go, Eliam did not make his *wants* known, dad left with a sibling who had indicated his *want*, dad had no ill *feelings* towards Eliam, Eliam felt *sad* now and how could the situation be handled differently in future? During the ToM intervention phase, behaviour stabilised at a low level with some nil behaviours recorded.

While the behaviour had already reduced during the preceding phase, an analysis of behavioural variables during the second phase of the programme also contributed to an understanding of the target behaviour and possible approach. In this case, suicidal ideation behaviour was proposed to be fulfilling an 'attention' function although possibly not in an obvious manner. Rather, the behaviour alerted an adult to Eliam's distress/lack of understanding and they generally attended to him in a comforting way. However, lack of successful resolution of this particular behaviour was proposed to be because attending others failed to enhance his level of understanding and Eliam was unable to verbalise this need. This understanding was actually based on knowledge of ASD gleaned from the earlier part of the course. While the trend for this target behaviour reversed during the applied behaviour analysis phase, it was felt that a prolonged period of recording would see a return to improving behaviour as noted in nil behaviour at both short and long-term follow-up.

Suicidal ideation behaviour reduced during the programme with nil behaviour recorded during both phases of intervention. Nil behaviours were also recorded at follow-up. However, conclusions regarding the effectiveness of the programme are

difficult due to two factors. Firstly, the ABA phase utilised features of social understanding thereby confounding results from the ToM phase (A). Secondly, there was a significant change in Eliam's schooling situation during the course of the programme. During the former part of the programme, Eliam was in and out of school with sickness and due to family dissatisfaction with the school environment. Eventually, Eliam was removed from school to be homeschooled. Eliam's mother attributed the changes in suicidal ideation behaviour to this change in schooling. However, while Eliam began homeschooling in week 5, he was withdrawn from mainstream education during week P2 (baseline), and thus data records do not necessarily support the behaviour change-school change conclusion.

Behaviour 3 – Mouthing objects. Mouthing behaviour consisted of putting inedible objects (including stones from the sidewalk) in the mouth and chewing on them. Besides the social obtrusiveness of this behaviour, Eliam's mother also expressed concern about both historical and potential medical complications. Data in Figure 8c show a stable trend in mouthing behaviour at baseline. Two reductions in data coincided with illness (P2 and week 2) or non-recording while Eliam was away from home for a period. The prolonged baseline period was due to reluctance by Eliam's mother to put intervention plans in place. She felt that this behaviour occurred 'all the time' and the incidence of behaviour was under-reported particularly as Eliam engaged in the behaviour when others were not present. Record-keeping was erratic and 'true' records were not produced until week 6. A notable peak at this point lends some support to the contention that behaviours were previously under-recorded. However, the general level of behaviour could also have been 'over-recorded' at this time due to a discrepancy between actual observation of behaviour and belief about estimates of rate of behaviour.

During the ToM intervention phase (B), Eliam's mother explained the effect of this behaviour on both herself (anxiety about health), Eliam (health risks) and others (socially inappropriate). A steep deceleration-improving trend was observed to low levels. During applied behaviour analysis (phase A), a sensory feedback function was proposed as underlying the behaviour and a replacement behaviour that was deemed

to be socially acceptable (by his mother) was introduced. A necklace was worn by Eliam to mouth. Behaviours were maintained at a low level and nil/negligible behaviours were recorded at follow-up. While it was clear that the behaviour was no longer a problem by the end of the programme, the lack of intervention data prevents drawing clear conclusions about this behavioural improvement.

Amy

Behaviour 1 – Non-compliance and tantrum behaviour. Non-compliance/ tantrum behaviours (crying, shouting, verbal aggression) occurred in response to Amy being requested or instructed to do something that she did not wish to do. The data presented in Figure 9a show a decelerating-improving trend in non-compliance/tantrum behaviour at baseline. During the ToM intervention phase (B), behaviour was initially fairly stable and then continued to decline to negligible levels. In an early incident, Amy's mother successfully used ToM techniques to stop an altercation involving Amy and her sister (e.g., visual supports to outline the expectations, what her sister *intended* and the effect of both girls' behaviour on each other and their mother). At week 5, Amy's mother reduced the complexity of verbal instruction (i.e., one instruction given at a time) to Amy on her own initiative and compliance improved markedly. The success experienced with this approach and a period of illness for Amy resulted in an extra week's data during this phase. Non-compliance continued at a negligible level during the ABA phase (A) and at follow up. At the end of the programme and during follow-up, most remaining compliance issues occurred around food intake (see behaviour 3).

Behaviour 2 – Non-sleep and disruption of the sleep of others. A lack of sleep was a major disruptive factor for the rest of the family with Amy sleeping as little as five hours per night and spending several hours awake during the early morning. During 'awake' periods, she would continually call out to other family members, request their company/assistance or get into bed with them - effectively preventing them from any further sleep. The data presented in Figure 9b show an accelerating-deteriorating trend in sleeping behaviour at baseline. During the ToM intervention

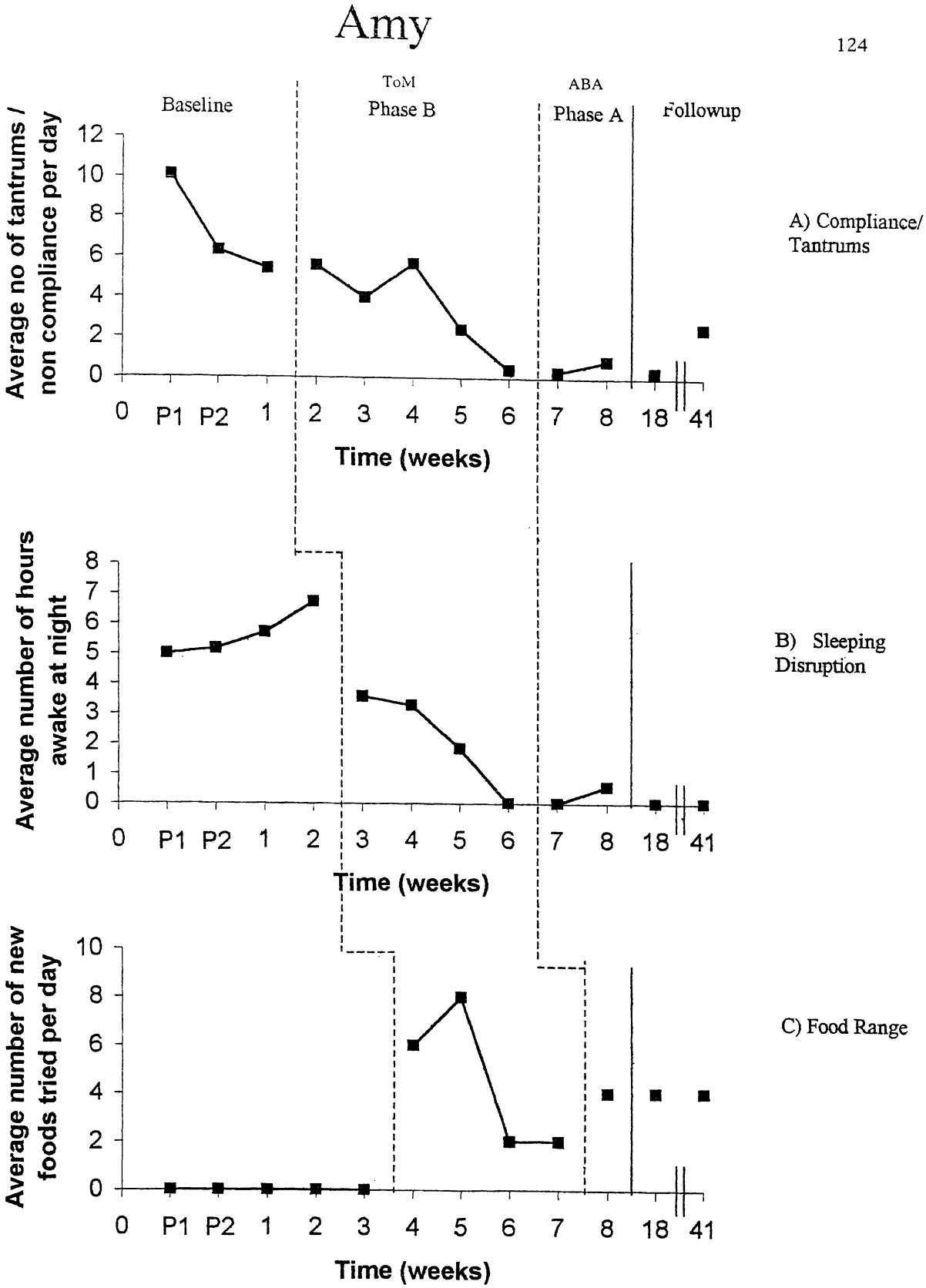


Figure 9. Comparison of two programme components over three challenging behaviours for a child with ASD – Amy.

phase (B), Amy's mother implemented a system using ToM techniques and visual supports. This consisted of a visual sign (a simple stick drawing of a person lying on a bed and a red cross to signify 'do not enter') on her parent's bedroom door combined with a visual and verbal explanation/depiction of the effects of her behaviour on other family members and a statement of expected behaviour and consequent effects on family members. Data records show that the baseline behaviour trend reversed and followed a decelerating-improved trend to nil levels. With the introduction of ToM techniques, Amy immediately ceased to disrupt others on awakening and quietly/ independently entertained herself. Over the remainder of the course, her sleep patterns improved until she was sleeping 7pm to 8am which was a total sleep period of 13 hours compared with a *maximum* of 10 hours pre-programme. Nil to low levels of target behaviour were maintained during the ABA phase (A). Much to mum's surprise, this behaviour never reappeared and Amy continued to have no sleep problems at short-term follow-up. At long-term follow-up, Amy was reportedly waking at night for periods of up to an hour. The ToM intervention was re-introduced and the behaviour ceased again.

Behaviour 3 – Restricted food range. Amy's restricted food intake and rigid patterns of approach to foods caused considerable stress for her mother. At the beginning of the course, Amy refused to eat/drink anything coloured green and had an aversion to lumpy texture. She refused to feed herself and would insist on being spoon-fed pureed baby vegetables. The data presented in Figure 9c show a stable nil level of attempts to try new foods and display independent feeding behaviour during baseline. During the ToM intervention phase (B), a higher level of appropriate behaviour was observed but with considerable variability. As food range is deliberately increased during this phase, data reflects more opportunities to engage in desired behaviour compared with baseline opportunities. However by week 5, Amy was observed to independently feed herself her vegetables over two consecutive nights.

Amy continued to display considerable resistance to attempts to introduce new foods throughout the programme. It was also noted that her mother was very hesitant to

challenge some of Amy's rigid behaviours (e.g., pureed baby vegetables) because she felt that Amy would choose not to eat at all. Food intake issues became the major source of non-compliant behaviour towards the end of the programme and while Amy's mother reported that food intake continued to be less than desirable, moderate gains were maintained over the applied behaviour analysis phase at both short and long-term follow-up. One positive feature of the focus on food range was that Amy began to independently feed herself and while attempts were made to remove baby vegetables from her diet, nutritional concerns expressed by her mother led to a change in outcome expectation i.e., from a *supplementation* to an *elimination* focus.

Elliot

Behaviour 1 – Non-compliance. Non-compliant behaviour consisted of Elliot's refusal to take 'no for an answer' and continual attempts to get what he wanted. As Elliot was non-verbal, this behaviour was a significant concern pre-programme and compliance issues took up a lot of Elliot's mum's time. In an attempt to encourage Elliot's communication attempts, his mother went with him to discover what he wanted. This led to multiple demands (e.g., in excess of 14 repetitive demands per day) on mum's time whereby she was literally following Elliot around the home to see what he wanted. Despite being instructed that he could not have/do something, this pattern of behaviour continued or deteriorated into tantrum behaviour (crying, kicking, hitting, throwing). The data presented in Figure 10a show a high stable trend in non-compliance behaviour during baseline. During the ToM intervention phase, pictorial supports were used to support mum's decision and facial representations of the effect of tantrum behaviour on other family members were utilised. The initial attempts to use ToM techniques produced avoidant and resistant responses from Elliot, but within a week, he accepted the use of visual supports and behaviour markedly improved. The data depicted in Figure 12a show a decelerating-improving trend to floor levels during phase B. By week 5, Elliot was copying the faces drawn for explanation. Moreover, mum no longer had to spend large quantities of each day trying to ascertain what he wanted as Elliot ceased repeating his demands. Nil/negligible levels of non-compliant behaviour were maintained during the applied behaviour analysis phase and at both short and long-term follow-up.

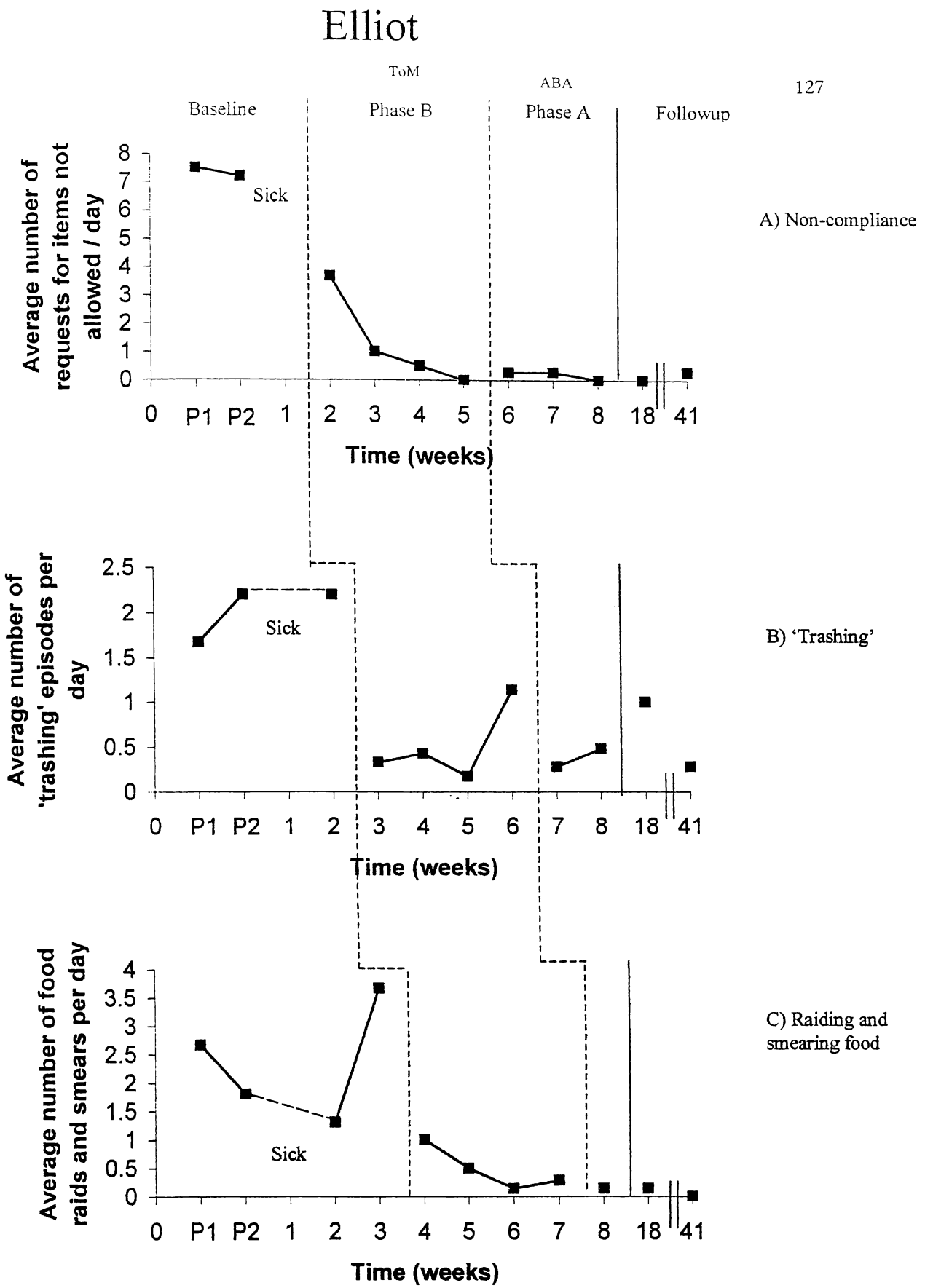


Figure 10. Comparison of two programme components over three challenging behaviours for a child with ASD – Elliot.

Behaviour 2 – Trashing. 'Trashing' behaviour consisted of Elliot up-ending toyboxes onto the floor. The resulting disarray caused considerable inconvenience to other family members and when toys were cleared away, Elliot would repeat the behaviour. The data presented in Figure 10b show an accelerating-deteriorating and stable trend in 'trashing' behaviour at baseline. During the ToM intervention phase, visual supports were used to communicate the effect of this behaviour on other family members and Elliot was required to focus on one 'pick-up' (clear away toys) per day. Due to the close monitoring of this behaviour during the course of the programme, it was discovered that the 'trashing' behaviour was actually an attempt to find three different primary coloured objects ('carries') which Elliot liked to carry about with him.

Elliot's mother proposed that 'carries' served the function of reducing anxiety and the function of the actual 'trashing' behaviour appeared to be 'tangible' i.e., obtaining the 'carries'. As the objects chosen for 'carries' were not consistent, it was difficult for Elliot to communicate his needs to others. Elliot's mother introduced an environmental change at this point (week 5) by re-organising the toyboxes (i.e., sorting out the toys, limiting access to some toys, labelling boxes with pictures of contents so Elliot could find his 'carries' more easily). However, this may have inadvertently led to an increase in the target behaviour as Elliot attempted to re-familiarise himself with the contents of each box. The data in Figure 10b show that behaviour levels dropped off but data remained variable during this phase. During the ABA phase (A), a low level of target behaviour continued to be observed. At short-term follow-up, low levels of behaviour were not initially maintained but behaviour did not revert to baseline levels. Long-term follow-up showed low levels of target behaviour.

At school, it was noted that Elliot appeared less anxious and had a reduced attachment to his 'carries' compared with the home environment. In the school context, the function of trashing behaviour was proposed to be boredom/escape and as a result a choice-board of 'play/activity options' was introduced with good results reported.

Behaviour 3 – Smearing/raiding food. 'Pantry' behaviour consisted of Elliot 'raiding' the pantry/fridge and taking large quantities of foodstuffs (e.g., biscuits, yoghurt) - most of which was smeared on the floor/carpet, bench or furniture. The data presented in Figure 10c show a high and variable pattern of 'pantry' behaviour with accelerating-deteriorating trend at baseline. Following close observation, the target behaviour was actually found to consist of two separate behaviours - an attempt by Elliot to feed himself because he was hungry or 'stealing' food to smear into the floor etc without the need to satisfy hunger. During the ToM intervention phase (B), visual supports were placed on the pantry/fridge. Visual techniques were also used to enhance Elliot's understanding of the effect of his behaviour on others and to shape his communication attempts. Target food items were placed in containers requiring Elliot to indicate assistance before being able to obtain them. The data in Figure 10c show a decelerating-improving trend in 'pantry' behaviours to low/negligible levels. These levels were maintained throughout the ABA phase (A) and at both short and long-term follow-up.

Over the course of the programme, techniques applied at home were also applied at school and behavioural/social understanding increases at school were noted (e.g., less extreme response to disruption and incidents that caused frustration). By the end of the programme, Elliot could successfully identify the basic emotions utilised in the ToM techniques and apply them to some social situations. He was reported to be making choices at school and attempts to establish communication with others was noted. At home, hand-over-hand techniques were no longer required for compliance. A change in reaction to requests for compliance was noted whereby Elliot was more likely to engage in 'tantrum' behaviour when a request was made. However, this was viewed in a positive manner by his mother and teaching staff as they felt Elliot was attempting to communicate his displeasure (as opposed to no response). Over the course of the programme and follow-up period, Elliot's mother successfully generalised the ToM approach to other siblings, situations and behaviours.

Summary of Behaviour Change for Group Two

Fifteen behaviours were observed during the course of the programme for Group Two (see Table 5). Over this period of time, all target behaviours (100%) changed in a positive direction (positive trend and/or level as determined by criteria outlined in Tawney & Gast, 1984). There was no evidence of nil or negative change in the data collected. However, two parent participants reported that they felt there had been no change in one of their three target behaviours. Amy's mother felt that Amy's restricted eating behaviour was still problematic at the conclusion of the programme. Data records show that Amy's intake of novel foods increased during this time and remained at moderate levels at follow-up compared with baseline levels. Elliot's mother felt that 'trashing' behaviour had returned to original levels by the end of the programme, however data records show the rate of behaviour throughout the programme and at follow-up was at lower levels than that recorded at baseline. These discrepancies demonstrate that parent's perceptions of change differed from the objective data collected. It is possible that as behavioural gains are made, parental expectations shift to higher levels and therefore observed change does not appear in line with the new expectation. It is also possible that while target behaviours did change in a positive direction, these particular behaviours were still considered problematic and stressful for the parents involved.

Table 5

Summary of the Direction of Behaviour Changes over the Course of the Programme for Group Two Participants

	Socialisation Behaviour 1	Communication Behaviour 2	Restricted/rigid Behaviour 3
Kyle	+	+	+
Bryan	+	+	+
Eliam	+	+	+
Amy	+	+	+
Elliot	+	+	+

Note. (+ = positive change).

An investigation into the behaviour changes as they relate to the triad of difficulties associated with ASD revealed that 100% (5/5) of the socialisation behaviours changed in a positive direction to floor/ceiling or non-problematic levels over the course of the programme. All communication behaviours changed in a positive direction during the programme to floor/negligible levels and remained there at follow-up. Four of these behaviours reached floor levels. Finally, all rigid/restricted behaviours changed in a positive direction and four of these reached floor/negligible levels over the course of the programme. Changes were maintained at follow-up. The remaining behaviour showed variability over the programme to ceiling levels but reduced to moderate levels where it remained at follow-up. All behaviours showed improvements compared with baseline measurements over the course of the programme and gains were maintained over long-term follow-up.

Summary of Course Components for Group Two

Positive behaviour changes were seen in 100% of the behaviours targeted for intervention in this group. An analysis of the effectiveness of each course component follows.

In a reverse situation from Group One, the effect of the ToM component was more evident in Group Two as it was consistently applied over a four week period for each behaviour. As the baseline period varied, so too did the length of the ABA phase (phase A) and results for this latter section are less robust due to less data points. Parent participants were considered to be competent in terms of ToM techniques before introducing the ABA phase and in many cases, floor/ceiling levels of behaviour were reached before the second phase of the programme was introduced.

During the ToM phase of the course (refer Table 6), 8/15 (53%) behaviours changed in a positive trend and level compared with baseline and one further behaviour (6.7%) showed positive changes in trend and level but with considerable variation in the latter. Therefore, using the *absolute* level change criterion (Tawney & Gast, 1984), a total of 9/15 (60%) behaviours showed positive changes in trend *and* level during the

Table 6

Summary of Data Trend and Level for ToM and Applied Behaviour Analysis (ABA) Phases of the Programme per Behaviour for Group Two Participants

Behaviour	ToM (phase B)		ABA (phase A) cf. ToM	
	Trend	Level	Trend	Level
Kyle 1	+	+	Repeat pattern to low level/var	
2	NC	++	Maintained at floor/low level	
3	+ (stabilise)	++	Maintained at floor level	
Bryan 1	+	++	Maintained at ceiling with variab.	
2	+	++	Maintained at floor level	
3	NC	+	Probe data - floor level	
Eliam 1	+	+ (overlap)	Maintained result, ↑ stability	
2	NC (↑ var)	+ (to floor)	-	NC
3	+	NC (-)	Maintained change, poss + level	
Amy 1	NC	NC	Cont. improvement to floor	
2	+	++	Maintained at negligible level	
3	+	+	Maintained at moderate level	
Elliot 1	+	++	Maintained at negligible level	
2	+	+	Maintained change	
3	NC	+	Maintained change	

Note. ++ = positive change to floor/ceiling levels, + = positive direction change, - = negative direction change, NC = no change in direction.

ToM phase. A further 4/15 (27%) of behaviours showed a positive change in level compared with baseline but no change in trend. One behaviour showed a positive change in trend but no clear change in level (Eliam, behaviour 3: mouthing objects). Therefore, during the ToM phase, 14/15 (93%) of behaviours changed in a positive direction and seven of these (50%) clearly reached ceiling or floor levels. (A further two behaviours reached floor levels during this phase with variability). The remaining behaviour showed no clear change in trend or level but reduced during the ToM phase to floor levels anyway (Amy, behaviour 1: non-compliance/tantrum).

The last column of Table 6 shows the changes in target behaviour during the administration of the second course component (ABA). The changes in behaviours were noted with reference to where they were at the completion of the first component (ToM). For example, during the ABA phase, Kyle-behaviour 1

('attitude'), shows a repeat of the patterns (positive trend, positive level) shown during ToM. In other words, this behaviour was observed to return to near-baseline levels during the applied behaviour analysis phase (i.e., gains during the ToM phase were not initially maintained) but followed positive changes to low/negligible levels as shown during the ToM phase. In another example, during the applied behaviour analysis phase, Amy-behaviour 2 (sleep disruption), shows that the behavioural gains made during the first half of the programme were maintained.

Of the fourteen positive behaviour changes noted during this phase, eleven of these gains were maintained at ToM phase levels during the applied behaviour analysis phase. One behaviour (Eliam, behaviour 3: mouthing objects) showed a possible improvement in level during the applied behaviour analysis phase. Two further behaviours showed maintenance of ToM phase gains but with increased variability during the applied behaviour analysis phase. Comparing results across the triad of ASD behaviours, 4/5 (80%) socialisation behaviours changed in a positive direction over the ToM part of the course and all five reached floor or negligible levels which were maintained at follow-up. One behaviour (Amy, behaviour 1: non-compliance/tantrum) reached floor levels during this part of the course but the contribution of the programme to this change is unclear.

One hundred percent (5/5) of the communication behaviours changed in a positive direction during the ToM phase with 4/5 of these reaching floor levels during this phase. One hundred percent (5/5) of the rigid/restricted behaviours also showed changes in a positive direction during the ToM phase with one reaching floor levels. There were no significant gains made during the applied behaviour analysis phase compared with the gains already observed and recorded during the ToM phase. One behaviour (Eliam, behaviour 2; suicidal ideation) showed a reversed trend in a deteriorating direction during the applied behaviour analysis phase but due to the small number of data points and the nil levels of behaviour observed at follow-up, this negative change is not considered significant.

Summary of results - Behaviour Change

Ninety seven percent (29/30) of the behaviours targeted during this programme showed changes in a positive direction. One behaviour showed no clear evidence of change. There were no deteriorations noted in behaviours compared with baseline. Parent participants reported positive behavioural outcomes in 93% (28/30) of cases and noted that 80% (24/30) of behaviours were either no longer evident or problematic at the conclusion of the programme. Moreover, parent participants showed evidence of generalisation of techniques across different behaviours, across different individuals and across different settings and they reported satisfaction with the techniques utilised and results obtained. All the socialisation and communication target behaviours and 80% of the rigid/restricted behaviours changed in a positive direction over the programme. Therefore it can be concluded that the programme effectively resolved challenging behaviours associated with ASD, for these ten parents, and that parents can successfully be taught to plan and implement the programme techniques and achieve successful results.

Table 7.

Summary of comparative data between the two phases of the programme: Applied Behaviour Analysis - ABA (phase A) and ToM (phase B).

	ABA				ToM			
*Behaviour change in desired direction	10/13 (77%)				14/15 (93%)			
	+	Floor	-	NC	+	Floor	-	NC
Socialisation	5/5	4/5	0	0	4/5	3/5	0	1/5#
Communication	2/3	0	1/3	0	5/5	4/5	0	0
Rigid/restricted	4/5	0	0	1/5	5/5	1/5	0	0

Note. *Compromised results removed from analyses. # positive outcome but not attributed to programme.

Table 7 shows a summary of the comparative data between the two phases of the programme. A comparison of the magnitude of change between baseline and intervention in each phase revealed that both techniques resulted in significant

changes in behaviour over the initial period of instruction (ABA: t_{obt}=3.899, $p < 0.01$; ToM: $t_{obt} = 4.04$, $p < 0.01$). An independent t-test found no significant differences between the two programme phases in terms of behaviour change (t = n.s, $p > 0.05$). Both phases were equally likely to produce behaviour changes in a positive direction. In summary, both applied behaviour analysis and ToM phases of the programme produced significant behaviour changes alone and neither technique was superior to the other.

Both sets of techniques produced gains in all triad areas associated with ASD. Over the course of the programme, all socialisation behaviours reached floor/ceiling or negligible levels in both groups. One positive behaviour change was not attributed to the programme (Amy, behaviour 1: non-compliance/tantrum). All the communication behaviours had positive results with 70% reaching floor/ceiling levels and the remainder showing moderate gains. Eighty percent of the rigid/restricted behaviours also changed in a positive direction and one (12.5%) reached floor levels.

Applied behaviour analysis techniques produced improvements in all socialisation behaviours, 66% of communication behaviours and 80% of rigid/restricted behaviours over the course of instruction (Group One). Thirty one percent of all behaviours reaching floor levels and these were all in the socialisation domain. The majority of the remaining behaviours (54%) changed in a positive direction during the applied behaviour analysis phase of the programme. One communication behaviour showed no improvement until ToM techniques were utilised and one rigid behaviour showed no clear change during either intervention period.

Using the ToM intervention techniques (Group Two), 100% of behaviours showed improvement in all domains. However, one socialisation behaviour was removed from analysis due to unclear attribution of effect. Of the remaining 14 behaviours, 75% of socialisation behaviours, 80% of communication behaviours and 20% of rigid/restricted behaviours reached floor or ceiling levels during the initial phase of instruction.

Both behaviour change techniques used during the programme were found to effectively produce change in the three triad areas associated with ASD. It would appear that rigid behaviours are less likely to be completely eliminated but this is expected given the nature of these repetitive types of behaviour. Moreover, some of the these target behaviours had no definable floor/ceiling level e.g., restricted food range. The results indicate that ToM techniques may be able to produce more floor or ceiling effects and within a shorter period of time compared with applied behaviour analysis techniques.

Results from both groups showed that the majority of gains (80-86%) were maintained over a short-term period. In the case of Group One, ToM techniques generally improved stability of gains in 20% of target behaviours subsequent to applied behaviour analysis intervention. In one case, ToM techniques improved the level of a behaviour that had previously failed to register movement in a positive direction. In contrast, applied behaviour analysis techniques did not appear to significantly vary the results gained using ToM techniques. The high level of maintenance of behavioural gains over time indicate that the procedures were robust and a large proportion of parent-participants were observed to generalise techniques successfully to other people, situations and behaviours. The transfer of skills to other people was an unexpected but desirable outcome of the ease and success experienced with these techniques.

Parent participants were able to effectively plan interventions, apply techniques and monitor outcomes using these techniques in a group situation. Maintenance of behaviour change using both sets of techniques was apparent over both a short and long-term follow-up period. Both techniques produced significant behaviour change, therefore, ToM techniques as utilised in this programme were *at least* as effective as applied behaviour analysis techniques in producing positive behaviour change over all groups of challenging behaviours associated with ASD. In this research, ToM intervention techniques showed some strengths over the applied behaviour analysis techniques in producing more floor/ceiling levels of behaviour and in shorter periods of time. Results support the teaching of ToM techniques as *at least* an equivalent

behaviour management strategy in children with an ASD. Parent-participants indicated that there were some additional factors that add weight to a preference for ToM techniques e.g., ease of instruction, the ability to intervene in behaviour without prolonged periods of analysis, parent preference (see chapter eight) and skill generalisation.

CHAPTER 4

Adaptive Behaviour

The focus of the previous chapter was on the specific target behaviours identified by parents prior to the start of the course. In this chapter, the adaptive behaviour of the children is of interest. Adaptive behaviour was not targeted directly by the intervention programme but rather, was recorded as a context for assessing generalisation of behaviour change.

Adaptive behaviour of individuals with an ASD is measured and compared using an objective measure: the Vineland Adaptive Behavior Scales (Sparrow et al, 1984). This measure allows comparison of the communication, daily living skills and socialisation domain scores of participants with scores of standardised age-reference groups. Adaptive behaviour data was collected using the interview-survey form in consultation with the parent. The measure was administered at baseline, at the completion of the programme and at both short and long-term follow-up. Levels of adaptive behaviour pre, post-programme and short/long-term follow-up are compared with both ASD and norm-based reference groups. In most cases, both experimental groups are combined as no significant differences were found between the two groups. The exceptions are noted. A summary of findings is presented at the end of this chapter.

Experimental Group Results Compared With Supplementary Norms for Individuals With Autism

Using Carter et al. (1998) supplementary norms for individuals with autism, the experimental group scores ranged from a percentile rank (PR) of 30 to 95 with an average PR of 68.5 at baseline. Thus prior to the programme (refer Table 8), the experimental group was functioning at an average level at or above 68.5 percent of the autistic population. Hence, as a group, the experimental sample could be considered to have 'above average functioning'. Immediately following the

programme, participants' adaptive behaviour scores ranged from a PR of 35-98 with an average of 80.8. Thus during the nine week programme, the experimental group increased their adaptive behaviour scores an average 12 PR points each. For the eight participants who underwent short-term follow-up data analysis, an average of a further 5 PR scores were gained over the 10 week follow-up period and another 5 PR scores were gained on average over the following seven month follow-up period (follow-up 2).

Table 8

Percentile Rank Scores for Combined Adaptive Behaviour for each Participant using Supplementary Norms for Individuals with Autism

	Baseline	Post-programme	Follow-up 1	Follow-up 2
Damon	75	90	95	99
Fern	45	60	65	80
Piripi	55	75	80	90
Hugh	95	98	-	99
Flynn	80	95	95	99
Kyle	85	95	-	95
Bryan	75	90	95	95
Eliam	80	90	90	95
Amy	65	80	85	90
Elliot	30	35	50	55

Note. Supplementary norms for individuals with autism from Carter et al., 1998.

At long-term follow-up (Table 8), participant scores ranged from 55-99 with an average gain of 9 PR points over short-term follow-up results (i.e., a combined increase of 14 PR points over the total follow-up period). All of these gains were significant (t_{prog}= 7.44, $p<0.05$: $t_{follow\text{-}up\ 1}$= 3.055, $p<0.05$; $t_{follow\text{-}up\ 2}$ = 3.74, $p<0.05$. All t-tests are reported for independent means). These results show the experimental group had made significant gains in terms of their level of functioning (compared with a normative group with autism) over the course of the programme and again over the 10 week and 7 month follow-up periods.

Figure 11 shows individual movement in PR scores using the supplementary norms. It is notable that 60% of participants were functioning in the top quarter of the autistic

population prior to the start of the course. During the course, this number increased to 80% of participants and the two remaining participants, Fern and Elliot, also showed large increases of 35 and 25 PR scores respectively over the course of the programme and follow-up periods. All participants therefore showed gains in adaptive behaviour scores over the course of the programme. There were no short-term follow-up data available for either Hugh or Kyle, but of the remaining eight participants, six showed small but significant gains in adaptive behaviour functioning over the short term (10 week) follow-up period. Seven participants showed further gains over the long-term follow-up period. By long-term follow-up, 90% of participants were functioning better than about 75% of the autistic norm group. Elliot and Fern were the only participants to show maximum gains during the follow-up period as opposed to during the course of the programme. It was notable that both these individuals had the lowest levels of adaptive functioning at baseline. The relationship between rate of behaviour gains and level of functioning needs to be clarified.

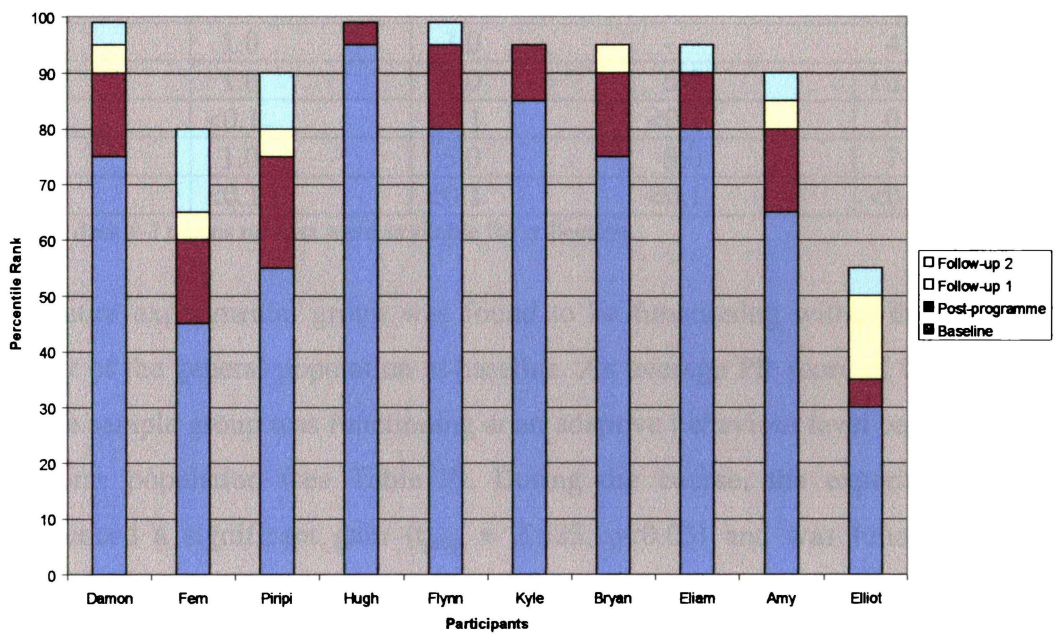


Figure 11. Average percentile rank gain for each child in the experimental group compared with ASD supplementary norms.

The Experimental Group and Norm-Based Comparisons

Compared with other individuals with autism, the experimental group was functioning at a high level. However, it is also important to compare these individuals with individuals within the 'normal' (age-equivalent, non-autistic) population. Hence, the experimental group scores were compared with scores of the relative norm group provided in the Vineland ABS Manual (Sparrow et al., 1984).

Table 9

Percentile Rank Scores for Combined Adaptive Behaviour for each Participant using Age-based Norms from the Vineland Adaptive Behavior Scales (Sparrow et al., 1984).

	Baseline	Post-programme	Follow-up 1	Follow-up 2
Damon	1.0	12.0	23.0	79.0
Fern	1.0	3.0	3.0	13.0
Piripi	0.2	1.0	1.0	3.0
Hugh	0.4	3.0	-	7.0
Flynn	0.3	13.0	12.0	55.0
Kyle	1.0	3.0	-	4.0
Bryan	1.0	3.0	6.0	10.0
Eliam	<0.1	<0.1	<0.1	0.3
Amy	1.0	5.0	8.0	7.0
Elliot	<0.1	<0.1	<0.1	<0.1

Note. A dash (–) means no data were available for collection.

The entire experimental group was found to be functioning within the lowest one percent of the general population at baseline. An average PR score of 0.59 indicated that the sample group was functioning at an adaptive behaviour level below 99.4% of the norm population (see Table 9). During the course, the experimental group experienced a significant gain (t_{prog} = 2.625, $p<0.05$) and was functioning at an average PR level of 4.3 i.e., below 95.8% of the norm population. Over the 10 week follow-up period, adaptive functioning increases continued compared with the norm population. While the gains were not statistically significant, the average adaptive functioning level of the group reached 6.6 (i.e., below 93.4% of the general population) by the end of the first follow-up period. Over the final follow-up period, adaptive functioning levels again increased but again were not considered statistically

significant. At this stage, the range of functioning varied from <0.1 to 79 PR points compared with a normal population. An average increase over the whole experimental group of 11.9 PR points showed that at long-term follow-up, the experimental group was functioning below 88% of the general population i.e., there was an overall average 11% gain in percentile rank scores.

Both sets of results (Table 9) indicate significant gains in adaptive behaviour scores for the experimental group over the course of the programme. A similar period of time elapsed over the first follow-up period but no further statistically significant gains were made during this time. A second follow-up revealed further gains but again they were not statistically significant. Overall, although gains were made by the experimental group, the *average* level of adaptive behaviour functioning of individuals with an ASD clearly within the lowest 20% of norm-based peers.

Individual Domain Changes per Participant Compared with Peer-based Norms

This section investigates changes with behavioural domains over the course of the programme. Data are presented as norm-based percentile rank scores and a PR of 50 is highlighted to represent functioning at or above the level of 50% of the general population. Using a more detailed analysis to examine changes within the behavioural domains of communication, daily living skills and socialisation for individual children revealed some interesting results.

Communication. Figure 12 shows communication domain scores. Recall that the average adaptive functioning level of the experimental group was 0.59PR prior to the course. However, individual analysis shows that Kyle was functioning at/above 47% of the 'normal' population with respect to communication prior to the course. No subsequent increases in this domain were noted during the remainder of the course and follow-up. Bryan was also functioning at/above 25% of the general population although he experienced a further gain in the communication domain during the short-term follow-up period to achieve an adaptive functioning at/above 39% of the general population level (with respect to communication). At long-term follow-up, he

was functioning at/above 32% of the general population. This apparent decline in functioning will be commented on below.

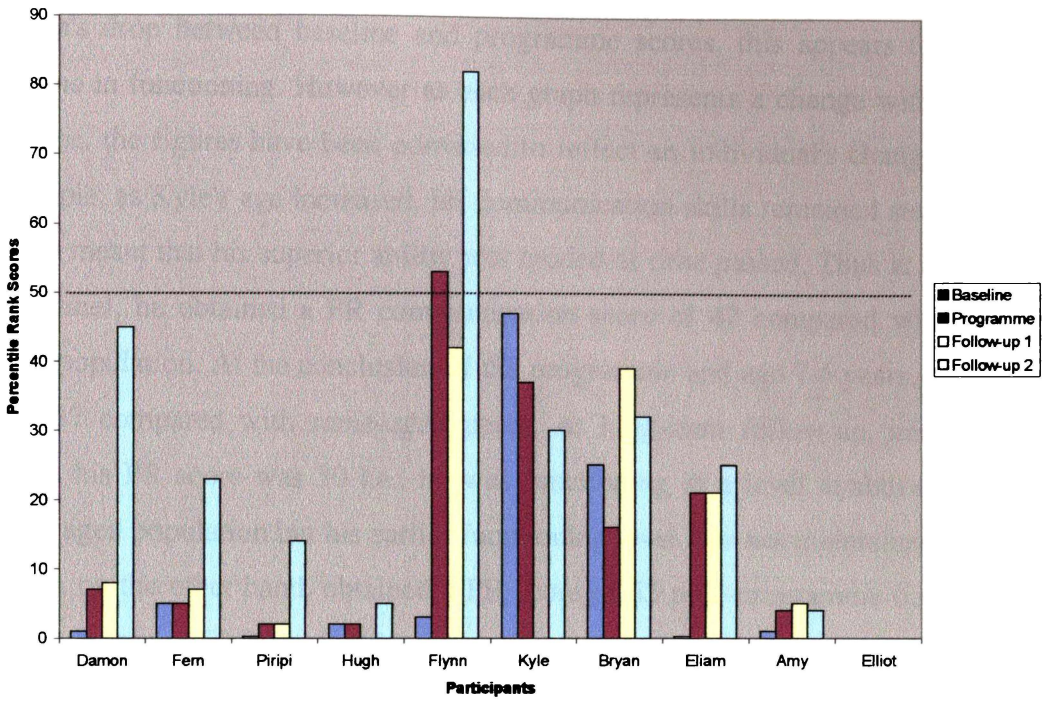


Figure 12. Individual percentile-rank changes in communication domain over the course of the programme and follow-up compared with (non-ASD) norm population.

All other participants were functioning at PR levels between <0.1 - 5 i.e., up to at/above 5 percent of the general population in communicative behaviour at baseline. During the programme, 50% of participants (n=5) evidenced no gains in the communication domain (including those with strengths already evident in this area). Of the remainder, gains varied from 1.7PR to 50PR. These results placed Flynn (who experienced the greatest PR score gain) at an adaptive behaviour level at/above 53% of the *general population* in terms of communication. Despite individual gains, changes in group scores over this part of the programme remained statistically non-significant (t = n.s; $p<0.05$).

On a group basis, changes over both the short and long-term follow-up periods were also statistically non-significant (t = n.s; $p<0.05$) in terms of communication.

However, again individual changes were masked by group averages. During the short-term follow-up period, Bryan experienced a gain of 23 PR points over programme levels of adaptive communicative behaviour. At this stage, Flynn appears to have dropped from programme levels of PR 53 to a follow-up PR of 42. As with Bryan's drop between baseline and programme scores, this appears to represent a decline in functioning. However as each graph represents a change with the passage of time, the figures have been corrected to reflect an individual's change in age. For example, as Kyle's age increased, his communication skills remained steady which in effect meant that his superior ability was eroded as time passed. Thus at age 7.3 years (baseline), he obtained a PR communication score of 47 compared with the same-aged population. At the conclusion of the programme and age 7.6 years, his PR score was 37 compared with *same-aged* peers. At long-term follow-up, and at age 8.2 years, his PR score was 30 i.e., he was functioning at a level at/above 30% of the same-aged population but his earlier functioning level was not maintained as he aged. Flynn, on the other hand, obtained a PR score of 53 post-programme (i.e., at age 7.1 years), a gain of 50 PR points from baseline (age 6.10 years). At short-term follow-up (age 7.3 years), he obtained a score of 42 PR points compared with same-aged peers. In other words, he also experienced a drop in his functioning level compared with previous scores. However, a further check at long-term follow-up (age 7.9 years), revealed he received a PR score of 82, i.e., he was functioning at/above 82% of same-age peers. In contrast to the results obtained by Kyle, Flynn's results showed an unsteady but increasing trend in communication skills over time.

Daily Living Skills. The daily living skills domain generally showed low initial scores across all participants at baseline (Figure 13). Percentile rank scores varied between <0.1 to 2 prior to the course. During the programme, 30% of individuals (n=3) showed no change in this domain. Of the remainder, most fell within a range gain of <0.1 to 7 PR scores. However, two individuals - Damon and Flynn, showed large gains from low to adequate adaptive functioning in daily living skills over the course of the nine week programme. Over the short and long-term follow-up periods, this gain continued for Damon until he reached a PR of 79 i.e., his daily living skills were at a level at/above 79% of the *general population.* Flynn

reached a final PR of 58 (at/above 58% of same-aged peers) during the same period. The only other gain in daily living skills during the follow-up period was for Amy who reached a final PR of 14. Despite changes in individual data, the experimental group as a whole did not experience statistically significant gains in daily living skills over the course of the programme or during follow-up (t = n.s, $p<0.05$).

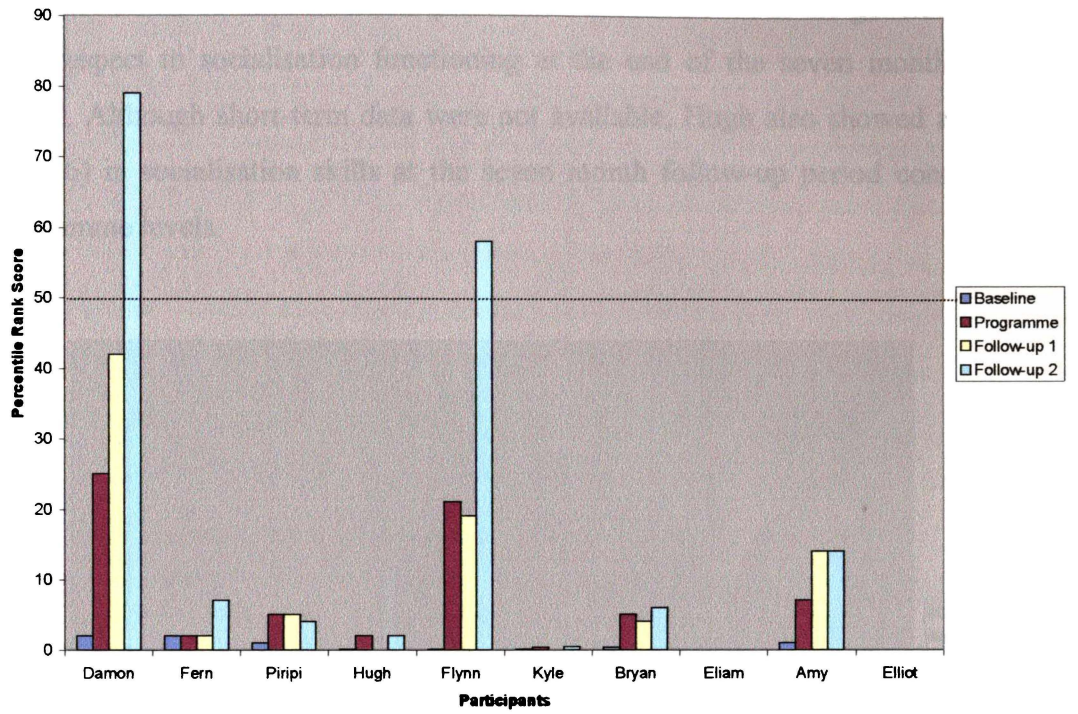


Figure 13. Individual percentile-rank changes in daily living skills domain over the course of the programme and follow-up compared with (non-ASD) norm population.

Socialisation. Within the socialisation domain, scores showed some variation in scores prior to the programme being implemented (Figure 14). Ninety percent of the experimental group fell within an adaptive functioning range of <0.1 to 5 PR scores. However Amy showed a strength in this area with an adaptive functioning level of 16 PR scores at entry to the programme. During the programme, 70% of participants showed gains in this domain ranging from 2 to 26 PR points. An average gain of 8.69 PR points for all participants over this period was significant ($t_{programme}$ = 2.86, $p<0.05$). During short-term follow-up, further gains were noted for 60% of the participants and adaptive functioning gains ranged from 1 to 23 PR points (t = n.s, $p<0.05$). During this period, Damon reached a socialisation PR level of 53, which

placed him at/above 53% of the *general population*. During long-term follow-up, further gains were made by 80% of participants. The remaining 20% of participants showed no change in scores compared with short-term follow-up levels. Increases in percentile rank scores ranged from 0.1 to 34 and there was a significant increase for the entire group over this period ($t_{\text{follow-up 2}} = 2.84$, $p<0.05$). Damon reached a final socialisation PR level of 87 which placed him at/above 87% of the general population with respect to socialisation functioning at the end of the seven month follow-up period. Although short-term data were not available, Hugh also showed a large gain (PR 36) in socialisation skills at the seven month follow-up period compared with programme levels.

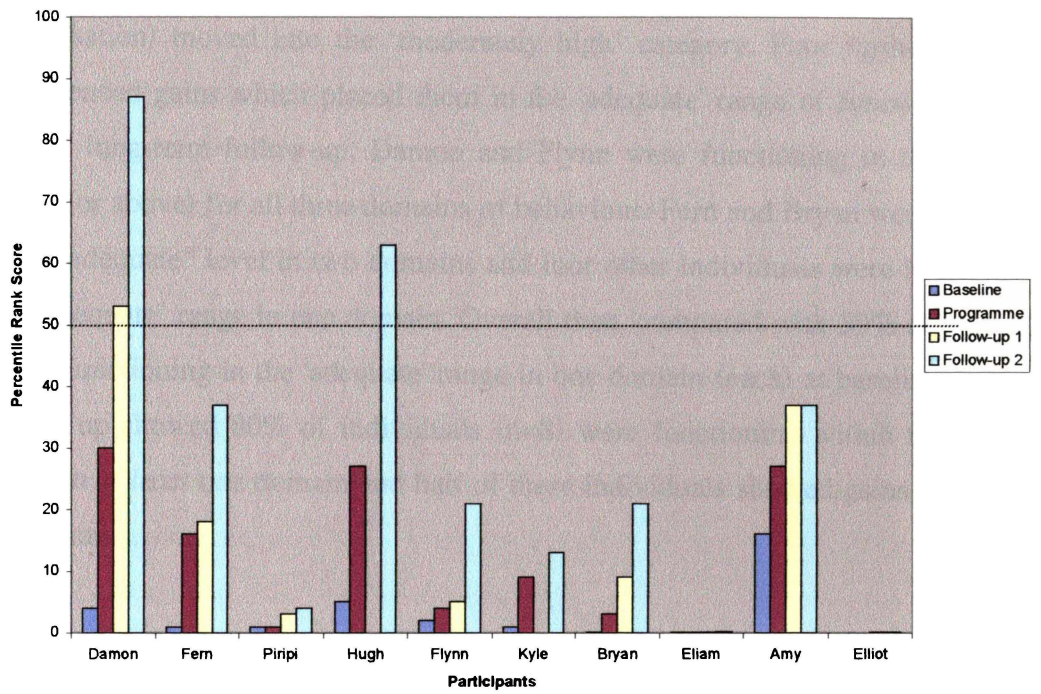


Figure 14. Individual percentile-rank changes in socialisation domain over the course of the programme and follow-up compared with (non-ASD) norm population.

Changes in Categories of Functioning

The Vineland Adaptive Behavior Scales manual provides a table for categorisation of individual's level of functioning, ranging through low, moderately low, adequate,

moderately high and high. The 'adequate' category covers two thirds of individuals. Three children (30% of participants) began the course in the 'adequate' range of adaptive functioning for one domain (Kyle and Bryan - communication, Amy - socialisation) for their age. During the course, five individuals moved up into the adequate range of adaptive functioning in one or more domain areas. That is, 50% of participants (n=5) displayed gains in adaptive functioning scores that enabled them to reach an 'adequate' level in one or more adaptive behaviour domains *during* the course of the programme. A total of eighty percent of the children (n=8) were functioning at an 'adequate' level (for their age, in one or more domain areas) at the end of the programme period. These gains were maintained over the short-term follow-up period. At long-term follow-up, some further positive changes were noted. All previous 'adequate' categorisations were maintained and one (Damon - socialisation) moved into the 'moderately high' category. Four further individuals experienced gains which placed them in the 'adequate' range of functioning. At the end of long-term follow-up, Damon and Flynn were functioning in the 'adequate' range (or above) for all three domains of behaviour. Fern and Bryan were functioning at an 'adequate" level in two domains and four other individuals were functioning in the 'adequate' range in one domain. Overall then, compared with 30% of individuals (n=3) functioning in the 'adequate' range in one domain (each) at baseline, long-term follow-up showed 80% of individuals (n=8) were functioning within the 'adequate' range in *at least* one domain and half of these individuals showed gains in more than one domain.

Forty percent of the children (n=4) moved from 'low' to 'moderately-low' categories of adaptive functioning during the programme and these gains were either maintained or improved upon during the follow-up periods. Piripi showed gains in two domains (communication and socialisation) from 'low' to 'moderately low' functioning between the end of the programme and short-term follow-up period. These gains were maintained over long-term follow-up. One individual, Elliot, showed no appreciable movement in terms of adaptive behavioural functioning over the course of the programme or follow-up in any domain. Compared with the normal-based population, Elliot's scores continued to place him below 0.1 percent of the population.

As comparisons with the general population norm group do not take into account Elliot's non-verbal presentation, this observation is not surprising. When compared with non-verbal individuals with autism (Carter et al., 1998), Elliot did experience gains of 25 PR points over the three behavioural domains of interest from baseline.

It is interesting to note that gains varied across adaptive behaviour domains for individual children. Some individuals showed appreciable gains in communication (e.g., Eliam), while others showed gains in daily living skills (e.g., Flynn, Damon). Still others showed most improvement in socialisation behaviour (e.g., Bryan, Hugh, Fern and Piripi). Those individuals who already had strengths in one domain prior to the start of the course, tended to show limited or nil gains in that domain over the course while domains of weakness improved (e.g., Kyle).

Ninety percent of participants (n=9) showed observable gains in adaptive functioning scores compared with an age-equivalent, non ASD population group. Of these children, the majority showed most gains in the socialisation domain, followed by daily living skills and lastly communication. As the programme specifically focused on increasing social understanding and as there was overlap between social behaviour and communicative behaviour, this result is somewhat expected. Nevertheless, it was particularly rewarding to note gains across all areas of adaptive functioning for most individuals during the course of instruction. These gains were sufficiently strong to be reported independently by parent participants at times during the course. The following are comments from five parents:

> My relationship with him (Damon) has improved because he is better able to explain himself when he gets upset.
>
> Fern has stopped repeating herself and uses communication instead.
>
> Piripi is talking more at school
>
> Amy seems much more relaxed in social situations. She also seems to understand how others are feeling.

Kyle shows less anxiety in some settings. He tells the family what he needs now.

Individual Improvement: Age-Equivalent Comparisons

While the comparison between domain change PR scores and norm-based group PR scores are useful, some individuals experienced marked rises in adaptive functioning domains. As such, age-equivalent data gives more meaningful comparisons in terms of individual improvement. Figure 15 shows changes within the three adaptive behaviour domains for each individual compared with the child's own age at four different stages over the study period: at baseline (a), over the course of the programme (b), at short-term follow-up (c) and long-term follow-up (d). These results show that the majority of individuals were functioning below their actual age level in all domains at baseline (Figure 15a). Kyle's communication level was the exception to this observation.

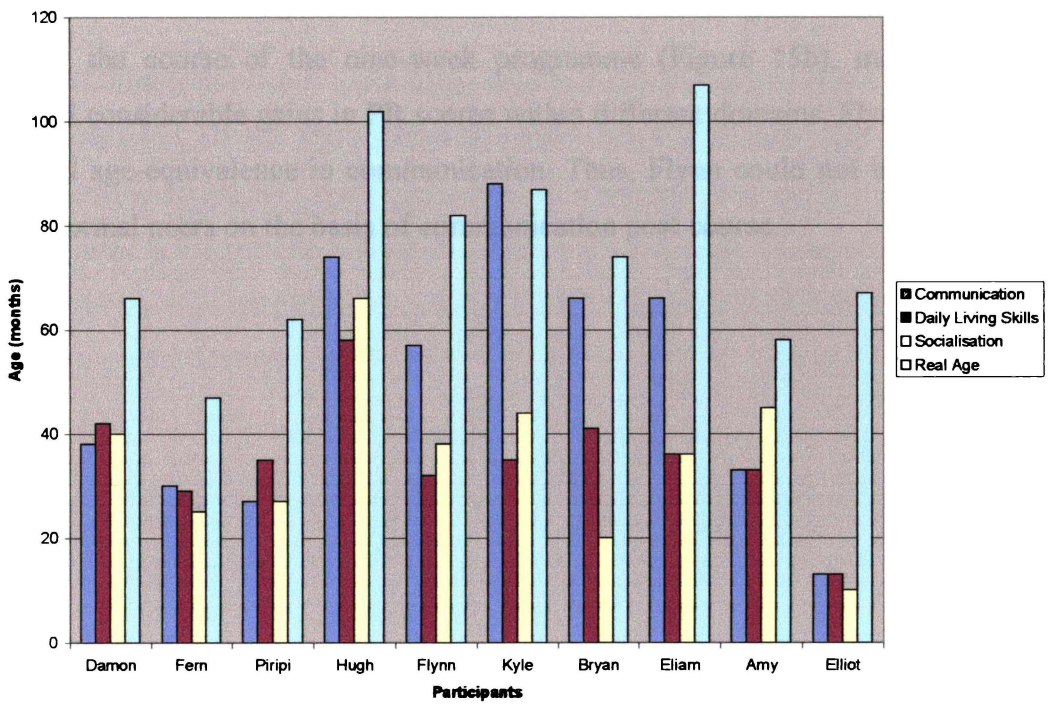


Figure 15a. Participant adaptive behaviour age at baseline compared with real age.

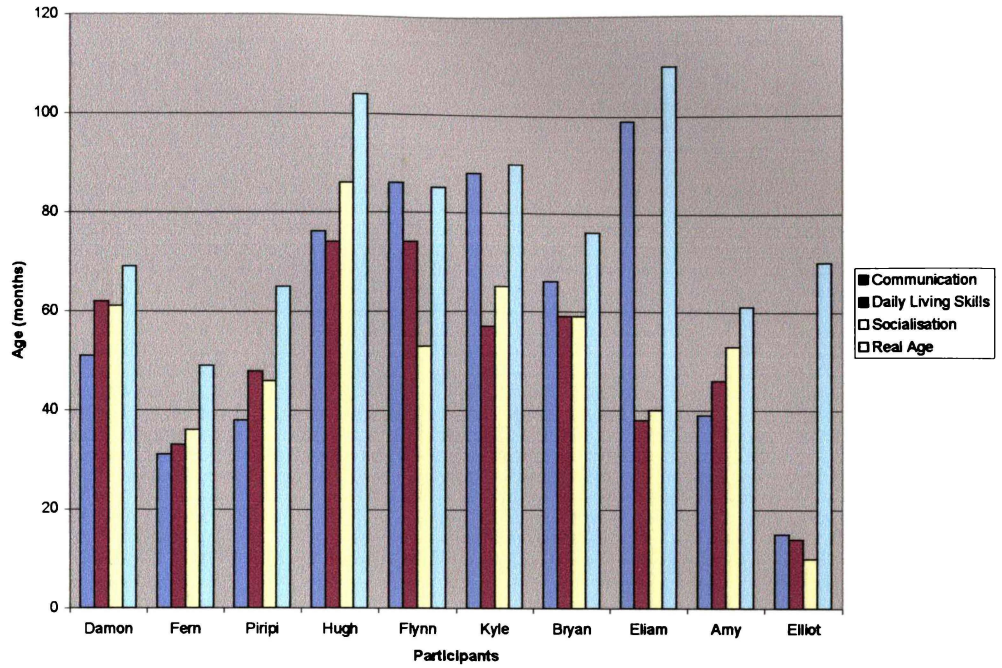


Figure 15b. Participant adaptive behaviour age at programme-end compared with real age.

During the course of the nine-week programme (Figure 15b), many individuals showed considerable gains in PR scores within different domains. Flynn for example, reached age-equivalence in communication. Thus, Flynn could not be differentiated from normal peers on the basis of communication post course.

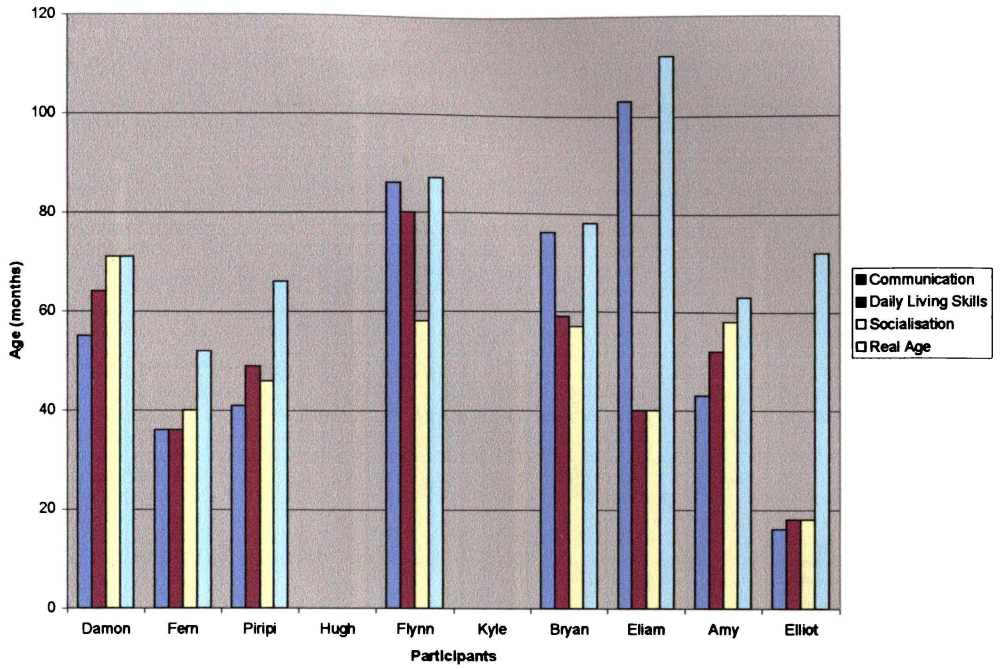


Figure 15c. Participant adaptive behaviour age at short-term follow-up (10 weeks) compared with real age.

By short-term follow-up (Figure 15c), Amy had almost reached age-equivalence in communication, Damon had reached age-equivalence in socialisation and Bryan and Amy had almost reached age-equivalence in communication and socialisation respectively. These results indicate that these children were functioning at an age-level equivalent to normal peers and could not be distinguished from these peers in the behavioural domains noted.

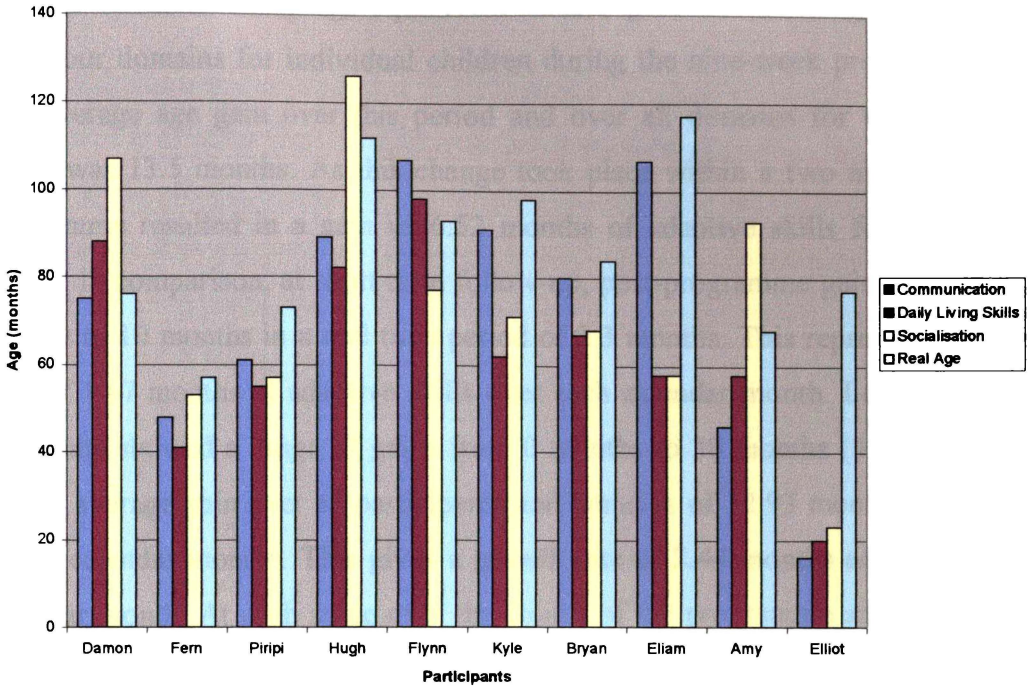


Figure 15d. Participant adaptive behaviour age at long-term follow-up (31 weeks) compared with real age.

At long-term follow-up (Figure 15d) a number of further improvements were evident. Damon was functioning at an age-equivalent level for communication and was functioning above his age in both daily living skills and socialisation skills. Hugh and Amy were both functioning above age in socialisation skills and Flynn was functioning above age level in both communication and daily living skills.

Gains in Adaptive Behaviour over the Course of the Programme

Group gains in Adaptive Behaviour

Results in the previous sections indicate that for the majority of children, major change took place *during* the course of the programme as opposed to *outside* the programme period. Changes over the course of the programme ranged from 0 months to 42 months of age (i.e., gains up to 3 years and 5 months) over a period of two

calendar months. Using age-equivalent data, Figure 16 shows gains in adaptive behaviour domains for individual children during the nine-week programme period. The average age gain over this period and over all domains for the experimental group was 13.5 months. As this change took place within a two month period, the programme resulted in a gain of 6.52 months of adaptive skills for each calendar month. In comparison, at short term follow-up, post-programme gains ranged from 2 months to 10 months in a real time period of 2.3 months. This represents an average gain of 1.47 months of adaptive skills over each calendar month. Long-term follow-up results showed a range of gains from 0 months to 38 months (3 years, 1 month) and an average gain over all participants and domains of 12.93 months over a period of 5.3 calendar months. This gives a growth rate of 2.44 months adaptive skills per calendar month. At each stage over the course of the programme and follow-up, the rate of skill acquisition was greater than that expected with the passage of time (i.e., one month skill acquisition per one month time elapsed). This finding indicates that the programme produced accelerated results which were maintained (albeit at a lesser rate) over time and following the withdrawal of intervention.

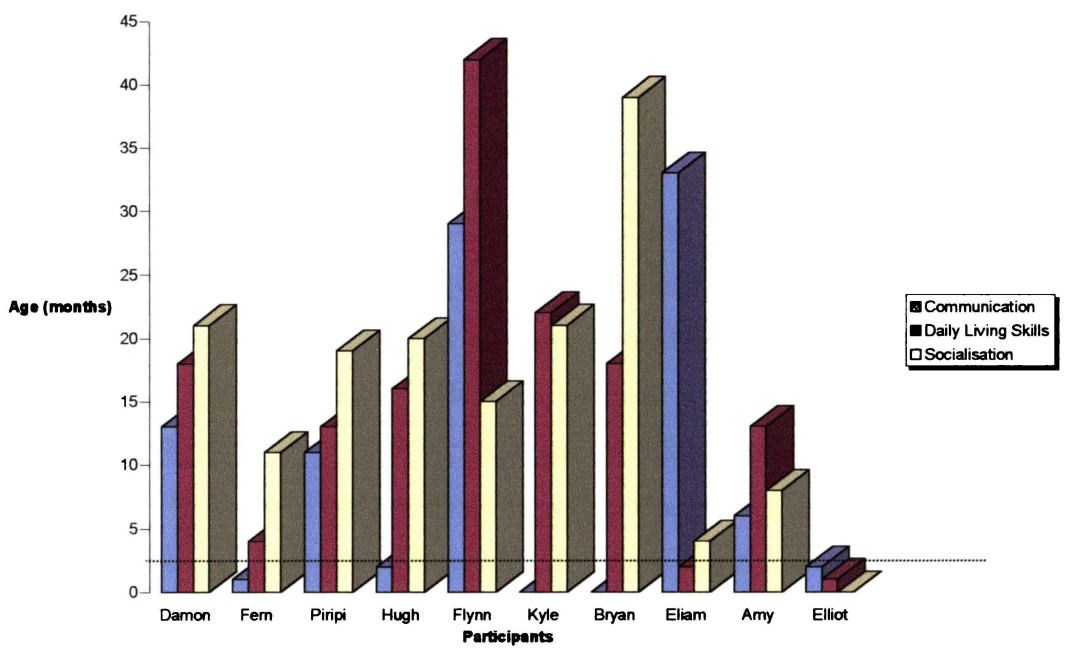


Figure 16. Gains in adaptive behaviour for each child over the course of the nine week programme. *Note.* Dotted line represents actual passage of time over course of programme.

Individual Gains in Adaptive Behaviour

A finer analysis of results at this point is useful for three purposes i) to determine the effect of the programme on each child's behavioural outcomes, ii) to determine the effect of the programme on each of the three adaptive behaviour domains and iii) to examine the differences found between the two groups. Accordingly, in table 10, each child's adaptive behaviour scores are portrayed as a proportion of skill acquisition (or change) over the course of one calendar year. A rate of 1.0 indicates a child has experienced gains of one year of behaviour skills over a period of one calendar year. For example, at baseline, Damon's communication score placed him at an age equivalent to 38 months. His real age was 66 months. In other words, at baseline Damon was functioning at a level approximately half of his chronological age (38/66 months = 0.58) in the communication domain.

This level of functioning equates to growth in communication skills of 6.9 months per calendar year (0.58 x 12 months = 6.9) in comparison to non-ASD peers. As the rate of skill acquisition was less than 1.0, Damon was not attaining a 'normal' rate of growth in terms of communication as he aged. An extrapolation of these results would see him communicating at an age equivalent to a 6.9 year old when he is 10 years of age.

At programme completion (a real time period of two months), Damon achieved a score which placed him at an age-equivalence level of 51 months (Table 10). His real age at this time was 69 months. This score showed he was functioning at a level approximately three-quarters of his chronological age (51/69 = 0.74) and his communication skills were growing at a rate of 8.8 months per 12 month period. Compared with the rate found at baseline which would have Damon functioning at the age of (0.58 x 69 months) 40 months, it is clear that the programme period has resulted in accelerated growth in terms of communication skill acquisition. Over a period of two calendar months, Damon gained 11 months of communication skills over and above the projected rate of growth found at baseline. Another point to note is a comparison between the two rates of skill acquisition. The difference between the

Table 10

Rate of Skill Acquisition over Three Behavioural Domains per Year for each Individual Participant

Participant	Domain	Baseline	Programme	Follow-up 1	Follow-up 2
Damon	Communication	.58	.74	.77	.98
	Daily Living Skill	.66	.90	.90	1.16
	Socialisation	.60	.88	1.0	1.41
Fern	Communication	.63	.63	.69	.84
	Daily Living Skill	.61	.67	.69	.72
	Socialisation	.53	.73	.88	.93
Piripi	Communication	.44	.58	.62	.84
	Daily Living Skill	.56	.74	.74	.75
	Socialisation	.44	.71	.70	.78
Hugh	Communication	.73	.73	-	.79
	Daily Living Skill	.57	.71	-	.73
	Socialisation	.65	.83	-	1.11
Flynn	Communication	.70	1.01	.99	1.15
	Daily Living Skill	.39	.87	.87	1.05
	Socialisation	.46	.62	.67	.83
Kyle	Communication	1.01	.98	-	.93
	Daily Living Skill	.41	.65	-	.63
	Socialisation	.52	.74	-	.72
Bryan	Communication	.89	.87	.97	.95
	Daily Living Skill	.55	.78	.76	.80
	Socialisation	.27	.78	.73	.81
Eliam	Communication	.62	.90	.92	.91
	Daily Living Skill	.34	.35	.36	.50
	Socialisation	.34	.36	.36	.41
Amy	Communication	.57	.64	.68	.68
	Daily Living Skill	.57	.75	.82	.85
	Socialisation	.78	.87	.92	1.37
Elliot	Communication	.19	.21	.22	.21
	Daily Living Skill	.19	.20	.25	.36
	Socialisation	.15	.14	.25	.30
Average		.53	.69	.70	.82

two rates is 1.9 months per year which may not seem particularly large, however, this increase in rate took place over a period of only two calendar months as opposed to a

year and thus the real rate of growth during the programme period is actually (1.9/2.0months) 0.95.

At short-term follow-up (Table 10), Damon achieved a score which placed him at an age equivalent to 55 months. Damon's age was 71 months which gave him a rate of skill acquisition equal to 0.77 or 9.3 months gain per year. The difference between this rate of growth and that found at the end of the programme period represents a gain of 0.5 months in a real time of 2.3 months, which equals a growth rate of 0.22. This rate is obviously much less than that observed at the end of the programme period (in other words, Damon's communication skills did not show huge increases over the short-term follow-up period) but they still grew at a higher rate than baseline.

At long-term follow-up, Damon achieved a score which placed him at an age equivalent to 75 months. His actual age was 76 months. His level of functioning and chronological age were now separated by only one month. This places his level of functioning well within the range of error and Damon is considered to be functioning at an age-appropriate level in terms of communication skills. This is also represented by the growth rate of (75/76) 0.98 or 11.7 months per 12 months which is very close to an expected 'normal' rate of 1.0 (i.e., one years growth in skills over a period of 12 calendar months). A gain of 2.4 months over the short-term follow-up rate in a real time period of 5.3 months shows a real growth rate of 0.45 during long-term follow-up. This rate is still less than the 0.95 growth rate observed during the programme and shows that over the long-term follow-up period, the rate of acquisition of communication skills for Damon was about half the rate gain experienced during the programme but still above that of baseline projections.

Analysis of the rate of skill acquisition during the programme (intervention) compared with after the programme (non-intervention) shows that Damon achieved a growth rate of 2.9 months in a real time period of 7.6 months (both follow-up periods) or 0.38 (Table 10). This result shows that the rate of skill acquisition after the programme was approximately one third of the rate observed during the programme and still well above baseline rates.

The rate of skill acquisition for all individual results per domain over the course of the programme and follow-up are depicted in Table 10. At baseline, Kyle is experiencing 'normal' rates of growth within the communication domain. At the end of the programme, Flynn is also experiencing 'normal' rates of growth in the communication domain. At the end of the combined follow-up period, Damon and Flynn are showing accelerated growth in daily living skills, Damon, Hugh and Amy are showing accelerated growth in the socialisation domain and Flynn is showing accelerated growth in the communication domain.

Changes in Adaptive Behaviour Rates of Growth per month over the Programme and Follow-up for the Experimental Group

Table 11 shows the average experimental group rate change results over the course of the programme and follow-up periods per domain. Daily living and socialisation skills showed the biggest gains over the programme period over the entire experimental group, followed by communication. During the combined follow-up period, socialisation skills continued to increase at twice the rate of the other two domains. However all domains showed reduced rates of skill acquisition compared with programme rates. On average, rate of skill acquisition over all domains increased at one quarter of the rate of growth recorded during the programme. As the programme period consisted of intense teaching and structured intervention sessions, it is not surprising that most change occurred during this time. However, it was encouraging to see that gains continued to be made at rates above baseline even when interactions with the researcher and other group members ceased. This result indicates that skills learnt during the programme and resultant growth in adaptive skills were maintained after the programme ended.

Table 11

Average Rate Change Results for All Participants in each Domain over the Course of the Programme and Follow-up

Domain	Programme	End of Programme to final follow-up (41 weeks)
Communication.	0.56	**0.16**
Daily living skills.	1.06	**0.16**
Socialisation.	0.99	**0.32**
Average rate	**0.87**	**0.21**
Average gain months/ year	**10.44**	**2.52**

Note. Scores corrected for child age change over passage of time over programme period.

Changes in Rate of Skill Acquisition Between Groups

A comparison of data between the two groups showed some interesting results when considering skill rate changes. This was the only section of adaptive behaviour comparisons that showed significant differences between the results of the two groups. Table 12 shows average rates of skill acquisition between the two groups during the programme and follow-up.

Table 12

Average Rates of Skill Acquisition within each Domain for both Groups over the Course of Programme and Follow-up

	Programme		Prog. to Follow-up	
Group	1	2	1	2
Commun.	0.74	0.38	0.29	0.03
DLS	1.31	0.80	0.16	0.16
Social.	1.31	0.99	0.41	0.23
Average	**1.12**	**0.72**	**0.29**	**0.14**

Communication. Neither group showed statistically significant results between acquisition of communication skills at baseline and the end of the programme i.e., both groups can be considered to come from the same underlying population at baseline (t = n.s, p>0.05, Table 12). In the period from programme to

long-term follow-up (follow-up 2), Group One participants showed a significant gain in communication skills whereas Group Two participants did not (t_{group1}= 4.9, $p<0.05$: $t_{group\ 2}$ = n.s, $p>0.05$). Over all ten participants, communication skills were found to be statistically significant post-programme (t_{total} = 2.912, $p<0.05$). Thus the significant result was actually due to changes of Group One participant data.

Daily Living Skills (DLS). In the baseline to end of programme period (Table 12), the whole group (n=10) was found to have statistically significant gains in daily living skills (t_{total} = 4.02, $p<0.05$). However closer analysis again revealed that members of Group One had significant results whereas Group Two members did not (t_{group1} = 3.14, $p<0.05$; t_{group2}= n.s, $p>0.05$). Over the post programme period, the whole group again showed a significant gain in daily living skills although this time neither Group One nor Group Two alone produced significant results.

Socialisation. In the baseline to end of programme period (Table 12), the whole experimental group produced statistically significant results (t_{total} = 4.10, $p<0.05$). However as for daily living skills, only members of Group One produced significant results for socialisation whereas Group Two members did not (t_{group1}= 9.08; $p<0.05$: t_{group2}= n.s, $p>0.05$). Over the post programme period, the entire group again had a significant result (t_{total}= 3.35, $p<0.05$) and again only Group One members showed significant results (t_{group1}= 3.39, $p<0.05$: t_{group2}= n.s, $p>0.05$). These results are summarised in Table 13.

Table 13

Results of Comparisons Between Group One and Two Members and Total Group per Domain over the Course of the Programme and Follow-up

	Communication		Daily Living Skills		Socialisation	
	Base-Prog	Prog-FU2	Base-Prog	Prog-FU2	Base-Prog	Prog-FU2
Group 1	n.s	n.s	s	n.s	s	s
Group 2	n.s	n.s	n.s	n.s	n.s	n.s
Total grp	n.s	n.s	s	s	s	s

Note. n.s = non-significant, s = significant results ($p<0.05$).

In summary, over the period from baseline to end of the programme, significant improvements were noted in the daily living skills and socialisation domain scores (Table 13). Further investigation revealed that changes in Group One data produced most of the significant results. No significant changes were noted in the communication skills from baseline to end of programme period in group data. Over the post-programme period, significant improvements were noted in all three domain areas with again, significant results only being found in Group One data.

Why Group One participants appeared to do better than Group Two participants can only be speculated on. One possibility that emerged during subsequent analyses – parent stress - is discussed further in chapter 8. There were no significant differences between the starting scores of children in either group for any domain. Consultation of notes taken during the programme revealed that as a group of parents, Group One appeared to work well together with the information supplied and they endeavoured to work systematically through target behaviour interventions. Group Two parents at times appeared to spend more time discussing the reasons behind their children's behaviour than working on target issues but these observations remain subjective and personal.

Summary of Changes in Adaptive Behaviour Scores

Behaviour changes within the domains of adaptive behaviour as measured by the Vineland Adaptive Behaviour Scales (Sparrow et al., 1984) were significant during the course of the programme. While individual gains varied across domains, all children experienced marked increases in their adaptive functioning level when compared with an ASD-based norm population. The majority of children also showed gains compared with a non-ASD, age-equivalent peer population and some attained 'normal' functioning status in one or more domains compared with this norm group. Most individuals made sizeable gains in terms of approaching (or exceeding) age-equivalence (non-ASD norm) in all domains during the course of the programme. The rate of skill acquisition during the programme was four times higher than post-programme rates. However, skill acquisition post-programme remained higher than during baseline. Comparisons of group rate changes suggest that most of the significant daily living skills and socialisation changes were due to Group One changes during the programme and to Group Two changes outside the programme period. Reasons for this remain speculative but parental stress (discussed in chapter seven) may provide some clarification.

As outlined in the introduction, the core triad of difficulties for individuals with an ASD are communication, socialisation and restricted interest range. Measurement of behaviour within each of these domains in terms of adaptive functioning was particularly useful for ascertaining the effect of the programme. Successful gains in all areas of adaptive functioning but particularly in daily living skills and socialisation indicate that the programme has specific relevance and benefit for this population.

CHAPTER 5

Attributions of Behaviour

As outlined in the methodology chapter, a simple rating scale was devised to measure the four major factors of attribution: consistency or stability of behaviour (i.e., how likely is it that the behaviour will occur again?), uniqueness/ distinctiveness (i.e., how likely is it that others will engage in this type of behaviour?), dispositional versus situational (i.e., how likely is the behaviour due to factors within the individual or due to factors in the environment?) and control (i.e., how likely is it that the individual is able to control his/her behaviour?). A copy of the scale is found in Appendix E.

The rating scale was administered at baseline, programme mid-point, programme end-point and at short and long-term follow-up periods. Group data are described separately and group outcomes are compared. Each attribution factor is analysed in terms of the effect produced by the two programme components (applied behaviour analysis versus ToM). Outcomes are summarised and weaknesses of the rating scale are discussed. In the final section, experimental outcomes are compared with previous research data and discussed.

Group Data Description

Group One

The data presented in Figure 17 show that at baseline, parent-participants felt the target challenging behaviours observed in their children were consistent and unique. Parents attributed the observed negative behaviour to dispositional characteristics and felt children had low control over their behaviour.

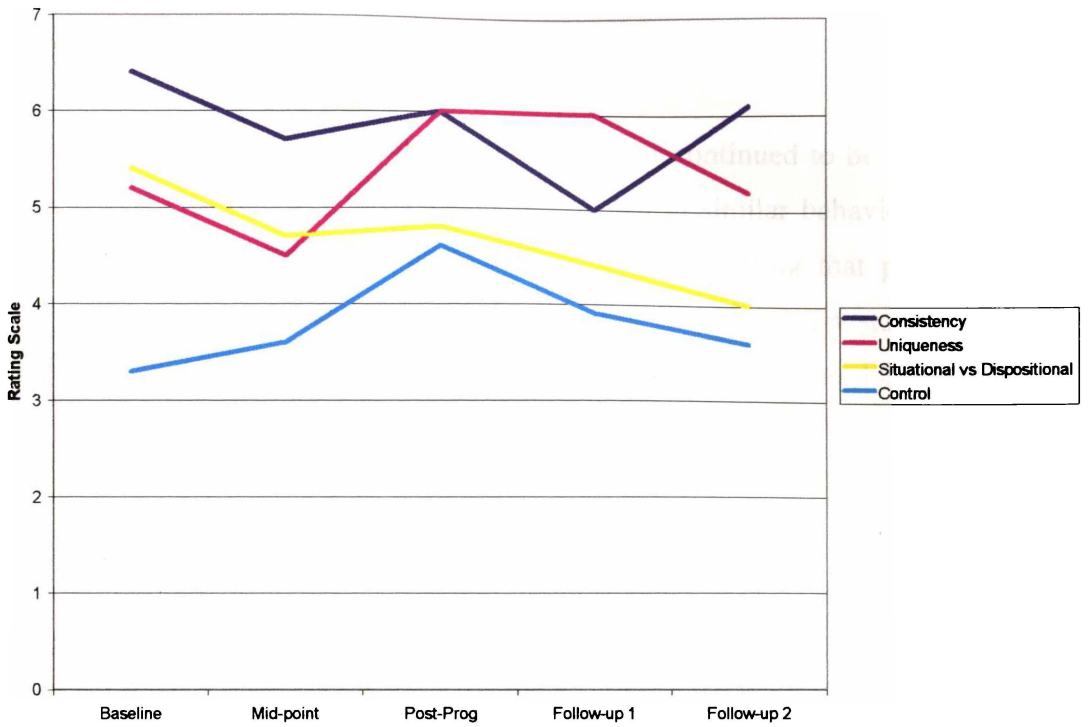


Figure 17. Changes in belief/attributions for Group One participants over the course of the programme and follow-up. NB. On the situational/dispositional scale, high scores represent dispositional attributions and low scores represent situational attributions.

At the mid-point and after the completion of the applied behaviour analysis material, Group One results showed some movement away from the extremes. Decreases were noted in parent's perceptions of consistency and uniqueness of behaviour. A tendency to attribute negative behaviour to dispositional factors was lower than at baseline. The issue of control remained at low scores i.e., the behaviour was not felt to be under the child's control.

At the conclusion of the programme and after the ToM material, participants still rated their child's negative behaviour as unique at higher levels than baseline. Ratings of consistency of behaviour had increased slightly from mid-point levels but remained below baseline (i.e., parents still believed that behaviour would occur again). However, ratings of control were elevated suggesting parents felt their child had more control over the particular behaviour observed. Consistent with mid-point

results, dispositional factors remained as the dominant explanation for behaviour but below baseline levels of attribution.

Short-term follow-up results showed that behaviour continued to be rated as unique over time i.e., others were not expected to engage in similar behaviours. However, ratings of the consistency of behaviour decreased indicating that parents did not necessarily have a perception that the behaviour would remain stable over time. Parents perceived the behaviour to be more within the child's control and behavioural attributions continued to be explained using dispositional attributions although at lower levels than previously noted.

Long-term follow-up showed a return to baseline levels of consistency, uniqueness of behaviour and control. The one enduring change was that observed behaviours were more likely to be attributed to situational factors than they were at baseline.

Group Two

Baseline data presented in Figure 18 show that Group Two participants felt that observed behaviours were of high consistency (i.e., were more likely to occur) but were not particularly unique (i.e., others were expected to engage in similar behaviours). Equal attention was paid to both situational and dispositional factors when making attributions and behaviour was generally considered to be outside the individual's control.

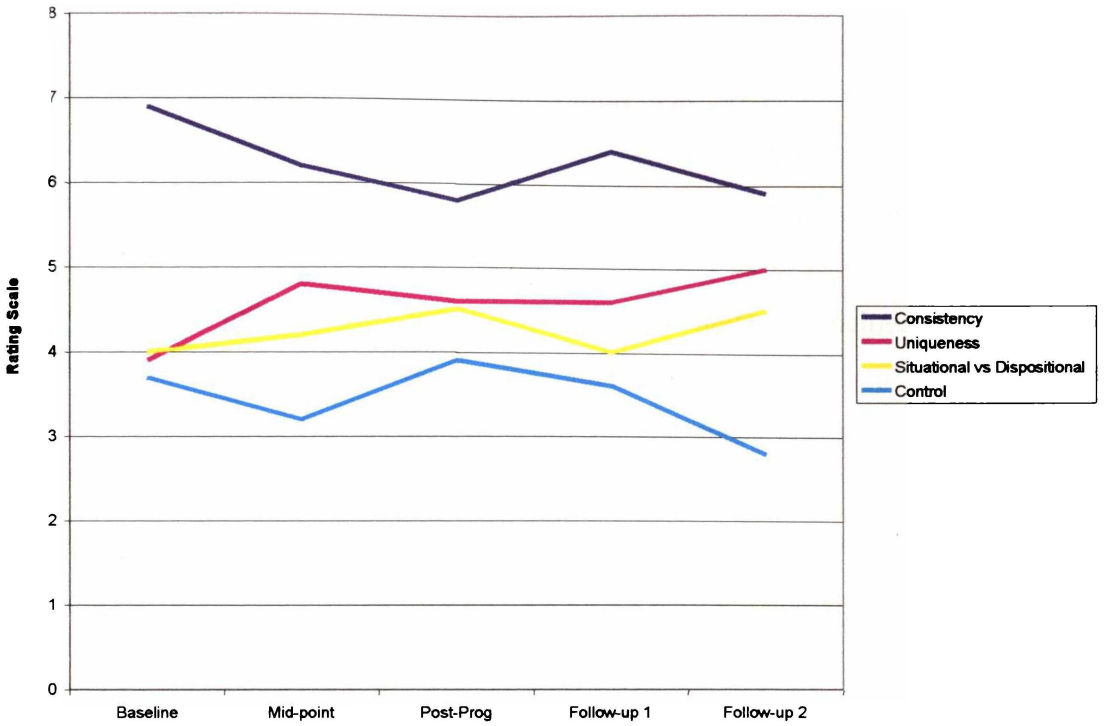


Figure 18. Changes in beliefs/attributions for Group Two participants over the course of the programme. NB. On the situational/dispositional scale, high scores represent dispositional attributions and low scores represent situational attributions.

At the mid-point of the programme and after ToM information and practice, high consistency was noted but at reduced levels compared with baseline. A rise was observed in the perception of uniqueness of the behaviours under observation. There was no noticeable change observed in the use of situational versus dispositional attributions and behaviour was still considered to be outside the control of the individual.

At the conclusion of the programme and after the applied behaviour analysis component of the course, consistency of behaviour continued to decline but remained at a high level overall. There was no change in the perception of uniqueness of behaviour. A slight tendency to use dispositional-based attributions over situational-based attributions was evident and observed behaviours were believed to be neither within nor outside the control of the individual.

At short-term follow-up, ratings of consistency and uniqueness of behaviour remained at programme levels. Consideration was given to both situational and dispositional attributions for behaviour and a slight decrease in the perception of control was noted in favour of individual's having little control over their behaviour.

At long-term follow-up, ratings of consistency of behaviour remained at a high level but below baseline rates. Behaviour was viewed as more 'unique' compared with baseline levels. There was a slight tendency for parents to utilise dispositional-based attributions when explaining child behaviour and behaviour was more likely to be considered to be outside the child's control compared with baseline levels.

A Comparison of Both Groups

At baseline, both groups of participants rated consistency and control of target behaviours at similar levels. Both groups believed that target behaviours were extremely likely to recur. Over the course of the programme and follow-up periods, attributions about the consistency or stability of target behaviours reduced i.e., child behaviours were perceived to be slightly less likely to occur compared with baseline perceptions. However, perceptions of the consistency of behaviour remained at high levels overall. Baseline measures also indicated that participants in both groups rated behaviours as being outside the control of their child i.e., the child was not considered to have the ability to control their behaviour. This perception persisted throughout the course of the programme and follow-up for Group Two, but Group One participants showed a tendency, during the course of the programme, to perceive their child as having more control over their behaviour. However, these ratings returned to baseline levels after the completion of the course.

In terms of perceptions of the 'uniqueness' of the behaviour, Group One participants had much higher baseline levels compared with Group Two participants. That is, Group One parents believed that other children were unlikely to engage in similar behaviours (compared with Group Two parents) prior to the commencement of the

course. As such it is difficult to compare the trends in the data. Both groups of participants were noted to *increase* their perceptions of the uniqueness of target behaviour at the completion of the course compared with baseline levels but Group One participant data was variable and returned to baseline levels at long-term follow-up.

At baseline, Group One participants tended to attribute target behaviours more to dispositional factors i.e., they believed that the exhibited behaviours were more likely to be explained by reference to the characteristics of the child (or condition of ASD) as opposed to characteristics of the environment within which the child functioned. Group Two participants did not show a preference for either dispositional or situational attributions at baseline. Both groups showed some moderation of their perceptions during the course of the programme. Group One participants moved towards situational explanations while Group Two participants moved towards dispositional explanations for behaviour. At long-term follow-up, both groups showed a tendency to consider both dispositional and situational explanations with a slight preference for the former. This was a noticeably larger shift for Group One participants as opposed to Group Two participants.

A Comparison and Discussion of Attribution Changes over the Two Course Components

Consistency. All participants perceived the target behaviours to be consistent or stable at very high levels at baseline. Throughout the programme and follow-up period, there was a decrease in the expectation that the child would engage in similar behaviours compared with baseline measures but attributions of stability remained at high levels overall for both groups. A decrease noted during the applied behaviour analysis component for both groups but the significance of this change is unclear. It could be proposed that the applied behaviour analysis information emphasised features of behaviour that were common to all challenging behaviours, and not specific to behaviours associated with ASD. Therefore, reduced expectations that the child would behave the same way in the future may reflect a change in the parent's

view of behaviour as 'challenging'. It is also possible that positive behaviour change observed during the applied behaviour analysis component of the course may have led parents to believe that their child would not be as likely to exhibit similar behaviour in the future. However, successful behaviour changes were also noted during the ToM component of the course and yet parental expectations of consistency were variable during this time.

Uniqueness. The single significant change during the ToM instruction period was a rise in the ratings of uniqueness, which rose beyond baseline levels and remained there throughout the rest of the programme and follow-up. This rise also occurred in Group Two data. An increase in perceived uniqueness of behaviour during ToM instruction could reflect understanding of the unique 'motivation' behind ASD-type behaviours, i.e., while behaviours may appear topographically similar, ToM information has increased parent understanding to the extent that they realise that other individuals are unlikely to be motivated by such factors and therefore behave in similar ways. Applied behaviour analysis training on the other hand, tended to lower the perception by parents that the target behaviours were unique to their particular child. This could be due to the approach utilised in this component whereby behaviours were viewed in isolation from the condition of ASD. Instead, behaviours were viewed from the perspective of a set of underlying functions which were common to all challenging behaviours. Parents may have increased their perception that the behaviours displayed by their child were *not* unique by virtue of the fact that non-ASD child behaviours could also be successfully changed using applied behaviour analysis techniques.

There is an alternative explanation for the changes noted in the perception of uniqueness of behaviour. As group participants discussed their child's behaviours, they may have felt that their particular child's behaviours were not as unusual as first assumed and therefore, perceptions of behavioural uniqueness may decline. On the other hand, sharing the unique features of ASD behaviours may have emphasised the uniqueness of behaviour and contributed to a sense of group identity.

Situational versus dispositional attributions. Over the period of the programme and follow-up, there was a gradual decline in the use of dispositional factors to explain negative behaviours for Group One participants. By the end of the long-term follow-up period, the tendency to use dispositional explanations had been modified to a consideration of both dispositional and situational factors in attempts to explain observed behaviours. In contrast, this decline was not evident at any point in the programme or follow-up period for Group Two participants.

There is an obvious difference between these two groups in terms of initial levels of attribution in this domain. Group One participants tended to attribute challenging behaviours to the dispositional characteristics of their child. In contrast, Group Two participants showed equal consideration of both dispositional and situational explanations at baseline. Both groups had exposure to the same material and yet only one group showed marked change. There was no consistent direction change in either part of the course – applied behaviour analysis or ToM. It is more likely, therefore, that the difference between the two groups was not due to course content but was an artefact of the different levels with which participants entered the programme. By the conclusion of the programme/follow-up period, both sets of group members reported consideration of both situational and dispositional factors reasonably equally. As the programme only appeared to alter the perceptions of Group One participants, it could be concluded that information provision has a moderating effect on extreme or very high levels of dispositional attributions.

Control. There was no consistency in the direction of control during the ToM part of the programme. Group One participants showed an increase in their perceptions of control while Group Two participants recorded a decrease following the ToM component. It is proposed that this discrepancy could be due to a weakness in the rating scale which led participants to monitor and rate different types of behaviour at different re-test periods. In 3/5 cases in Group One, the behaviour measured at post-programme was different to the behaviour measured during the programme and at baseline. Of the two participants who did compare similar behaviours across baseline, mid-point and post-programme periods, one showed an

increase in the amount of control attributed to their child's behaviour, while the other showed a corresponding decrease in the level of control attributed to their child's behaviour.

In a similar analysis with Group Two data, three of the five participants were found to have observed the same behaviour throughout the programme period. The difference in these cases though was that all participants rated increasingly higher levels of perceived control during the ToM component. While the overall ratings of control reverted to baseline levels at short-term follow-up, these results tentatively lend support to the proposal that beliefs about child control (over behaviour) could increase with successful behavioural resolution although these changes do not appear to be maintained over time.

Beyond 'weaknesses' in the rating measure, some level of explanation for these disparate outcomes can be found in the content of the ToM component. On the one hand, an increase in the awareness of how ASD impacts on the child's behaviour could *lower* a parent's belief that the child has control over their behaviour. For example, understanding that hitting behaviour is a reaction to sudden change in the environment (as opposed to a previous belief that the behaviour was a deliberate attempt to manipulate others) would increase the likelihood that the child's behaviour would be attributed to a situational context over which he/she has little control. An alternate explanation which could *raise* the parent's belief that the behaviour was under the child's control is observing positive behaviour change over the course of the programme. In this case, improvement in target behaviours may signal to the parent that the child has increased control over his/her behaviour.

In contrast to the ambiguous results shown in the ToM part of the course, the applied behaviour analysis component produced increased ratings of control by both groups i.e., parents perceived their child to have more control over their behaviour. While the increases are not large enough to warrant detailed analysis, it could be proposed that the content of the applied behaviour analysis material (in particular, the focus on identifying the function underlying behaviour and to a lesser extent – contingency

manipulation) could lead to the perception that the child had more control over their behaviour than previously expected. The applied behaviour analysis part of the programme viewed challenging behaviours without reference to the condition of ASD. It is feasible that previous (baseline) perceptions of the child having low control over their behaviour were based on an 'allowance' being made because the child had ASD. Observing successful behaviour change without specific reference to the underlying condition may have allowed parents to change their initial perceptions.

Long-term follow-up results indicated no change in the perception of control in either group compared with baseline. As such, the observed variance in controllability during the course of the programme does not appear to be maintained over time and firm conclusions are unreliable. This area could benefit from further study and clarification.

In summary, parents of children exhibiting challenging behaviours associated with ASD tend to rate target behaviours as being consistent and unique. They pay attention to both dispositional and situational factors, with a slight tendency to favour dispositional factors before training. They believe the child does not generally have the ability to control their behaviour.

The application of ToM material produced little enduring change in attributional factors compared with baseline attributions. The exception to this observation was that behaviour was considered to be slightly more 'unique' following ToM instruction. Presentation of applied behaviour analysis material produced a decrease in the perception of consistency and a slight decrease in perceptions of uniqueness of behaviour.

There are two significant weaknesses in this section; (a) the measure used and (b) the different baseline ratings between the two comparison groups. The rating measure used in this analysis was constructed for the purpose of this study. It was not tested independently to establish construct validity and/or reliability. In addition, the two comparison groups shared similar baseline ratings for consistency and control of

behaviour but had different baseline starting measures for both uniqueness and situational versus dispositional explanations. These discrepancies in starting points limit the validity of comparative analyses and the results outlined here should therefore be viewed with caution.

Comparison of Results with Previous Research

The contention that observers are generally more likely to attribute behaviours to dispositional factors when behaviours are unique and consistent, was supported by Group One data. Group Two data was inconclusive in this regard as the tendency to attribute behaviour to dispositional as opposed to situational factors was not obvious at any stage over the course of the programme. It is noted that while ratings of uniqueness were weak in Group Two data compared with Group One data, there was nevertheless a tendency for Group Two participants to perceive observed behaviours as 'unique' rather than 'usual'.

In the introductory section, it was noted that parents of children with difficult behaviours tend to attribute negative actions (challenging behaviours) to stable dispositional traits (Baden & Howe, 1992). The findings in Group Two data did not support this statement. There was no evidence in this group that parents attributed challenging behaviours to dispositional rather than situational factors. Group One participants initially utilised dispositional attributions but this tendency decreased over the course of training. While an observer unfamiliar with the child may attribute challenging behaviour to dispositional factors, it is possible that a close relationship with the child will provide the observer with various alternative attribution opportunities. Parents are often acutely aware of the negative behaviour exhibited by their child. They also have access to a wide range of other behaviours. This knowledge gives the parent additional information about the child such that attributions about negative or unexpected behaviour are attenuated and judgements concerning the child's 'inherent character' are not necessarily made. The parent is also often aware of the setting events or triggers to behaviour and has probably already identified connections with environment variables in an attempt to make sense out of

their child's behaviours. Finally, parents who choose to participate in a research project of this nature are likely to have focused and positive relationships with their child. Parents chose to participate on the basis of understanding that the programme would enhance parent-child relationships. As a parent believes or has knowledge of the child's positive features, the tendency to use negative, stable dispositional factors to explain his/her behaviour decreases.

In an interesting aside, consideration was given to the mood of the participants. As recalled from the introduction, depressed mood will decrease the likelihood of making dispositional attributions for observed negative behaviour. As part of results analyses, it was discovered that 4/5 members of Group Two had significant poor health/mood profiles including depression/ negative mood (see chapter seven). No Group One members had significant profiles. Thus, the low dispositional attribution tendency noted in Group Two data could be a result of negative mood. While this finding would support the large body of research which demonstrates the influence of mood on attributions, a consideration of programme and follow-up results indicate that this conclusion must be approached with care as participant stress profiles varied but with no notable changes observed in the use of dispositional versus situational attributions.

Previous research (as outlined in the introduction) indicates that observers are more likely to have negative interactions with individuals who display negative behaviours attributed to consistent, dispositional factors. Using the Questionnaire of Resources and Stress - QRS (see chapter seven), an improvement in the parent-child relationship was noted over the course of the programme. This improvement coincided with a reduction in the emphasis placed on situational factors. These results indicate some support for the notion that interactions between parent and child improved in conjunction with a corresponding decrease in the use of dispositional attributions. However, the causal linkage between these two factors is not clear and requires further investigation.

Both groups generally rated the observed behaviours as being outside the control of their child (or at least equally within/outside the control of the child). According to the introductory discussion, when behaviour is seen to be outside the control of the individual, negative emotional responses from the carer are less likely to occur and helping behaviour is more forthcoming. This statement appears to be supported by the findings here. Improvements in the parent-child relationship over the course of the programme were both verbally reported and independently recorded using QRS profile scores (see chapter seven). However, it should also be noted that the parents who participated in this research actively chose to participate in a programme designed to examine their child's behaviour and thus they may have been more likely to display assistance and positive emotions towards their child than someone who may have not chosen to participate.

CHAPTER 6

Parental Locus of Control

In this chapter, the focus turns to parent-participant measures. Of particular interest is parent perceptions of their efficacy in parenting, beliefs about own responsibility for child behaviour, control over child behaviour and perceptions of child control over the parent's life. These four concepts were rated using the Parent Locus of Control scale (PLOC) (Campis, Lyman, Prentice-Dunn, 1986). The measure was completed at baseline, at the programme midpoint, programme endpoint, and at the short and long term follow-up periods. Each concept is discussed separately in terms of outcome and group results are compared. A general discussion follows at the end of the chapter.

Parental Efficacy

Parental efficacy is the ability of parents to assess the effectiveness of their parenting techniques in terms of desired child behaviour outcomes. This factor requires parents to rate their ability to predict their child's behaviour in a given situation, expectations of their ability to effect or change the child's behaviour and their views on the effectiveness of chosen behaviour management techniques. Each statement is rated using a five-point Likert scale ranging from strongly disagree to strongly agree.

The range of possible scores for parental efficacy was 10-50 with higher figures representing poor beliefs in parental efficacy. At baseline, scores for the entire experimental group ranged from 13-37 with an average score of 20 (refer Table 14). As this score is below the scale midpoint, we can surmise that the experimental group had high parental efficacy. In other words, parents *did* believe they had the ability to change the behaviour of their child *before* starting the course. There were no significant differences between the two groups at baseline.

Table 14

Group Average Scores for Parent Efficacy Throughout the Programme and Follow-up.

	Baseline	Prog midpoint	Prog endpoint	Follow-up1	Follow-up2
Group 1	21.8	19[s]	19.4[s]	14.5*	19.8
Group 2	18.2	19.2	16.4	16.3*	19.2
Entire Group	20	19.1	17.9	15.3	19.5

Note. s = significant result ($p < 0.05$) compared with baseline. * indicates an n=4.

At the programme midpoint, there were also no significant differences between the two groups and the entire experimental group scores ranged from 11-35 with an average score of 19.1. Group analysis showed that Group One participant scores significantly decreased from baseline scores over this period ($t_{group1} = 3.29$; $p<0.05$) whereas no significant changes were noted for Group Two data (t_{group2} = n.s; $p> 0.05$). This indicates that Group One participants had a significant improvement in parental efficacy within four weeks of the programme commencing and after receiving the applied behaviour analysis material.

At the programme endpoint, scores ranged from 11-34 over the entire group with an average score of 17.9. While the average score continued to improve, the variance in individual scores meant the average change over all participants was not significantly different compared with baseline figures (t = n.s; $p>0.05$). However, Group One results still showed a significant improvement compared with baseline figures ($t_{group1} = 3.54$; $p<0.05$: t_{group2} = n.s; $p>0.05$) possibly maintaining the improvement noted at programme midpoint.

At the short-term follow-up point, participant scores ranged from 13-23 with an average of 15.3. Again, while the average score continued to drop, individual score variance meant that the improvement was not statistically significant from baseline figures for the entire experimental group (n=8) and there were no differences noted between the two groups, although each was significantly different from the programme endpoint.

At long-term follow-up, scores ranged from 11-32 with an average score of 19.5. These figures show no significant departure from baseline figures and tend to indicate that parental efficacy beliefs reverted to baseline levels over time. This was not an unexpected outcome given that parent-participants were no longer required to 'analyse' and report on their parenting behaviour as required during the period of the programme. No group differences were noted at this stage.

Over the course of the programme and short-term follow-up, group averages showed that parental efficacy beliefs improved, although results were seldom statistically significant (refer Table 14). Significant improvement was noted for Group One four weeks into the programme and again at the programme endpoint. No such changes were noted for Group Two participants. One member of Group One - a parent of Chinese origin - had poor parental efficacy beliefs, i.e., she reported low beliefs about being able to affect her son's behaviour throughout the programme. Although her scores steadily dropped indicating improving parental efficacy, they remained sufficiently high so as to elevate Group One average scores upon which the comparative statistical studies were made. For example, at the end of the programme, Group One participants had an average score of 19.4 compared with a Group Two average of 16.4. If the above participant score was eliminated, the new Group One average (15.8) is at least equivalent if not better than the Group Two average. During short-term follow-up data collection, this participant was unavailable. At this point, Group One averaged a parental efficacy score of 14.5 compared with an average of 16.3 for Group Two.

The lower the score, the more the individual believes that she has the ability to change the behaviour of her child. In the entire experimental group (n=10), the average score at baseline was consistently below the midpoint of the scale indicating that participants had positive and healthy parental efficacy. In a small group study (n=60), the PLOC has been found to differentiate between parents requesting/seeking help for parenting issues versus those who report no difficulties with parenting. Using these group means (19.27 and 17.62 respectively), we could tentatively surmise that the experimental group was more likely to seek help with parenting issues at baseline.

However, at programme end and short-term follow-up, they were unlikely to consider they had difficulties with parenting issues.

Interestingly, long-term results indicate a return to baseline beliefs with regard to parental efficacy thereby suggesting that changes were not robust over time. Depending on which comparative figures one uses, this reversion to former belief patterns may or may not be considered problematic. As reported in Chapters One and Two, long-term behaviour changes were basically maintained over time and parents reported satisfaction with their own abilities in managing their child's behaviour, therefore belief about parental efficacy appears to be at odds with behavioural outcomes and indicators. While perhaps resistant to change over time, the initial (and end) parental efficacy outcomes remained below the scale midpoint and thus the reversion to baseline level is not viewed with concern here.

Parental Responsibility

Parental responsibility refers to parent's beliefs about their degree of responsibility for their child's behaviour. The possible score range for this factor was 10-50 with higher scores indicating that the parent does not accept any responsibility for the child's behaviour/s. Parents who rate themselves at this end of the scale are more likely to minimise their part in either the negative or positive behaviours displayed by their child and are more likely to believe that behaviour is inherently within the child rather than being a function of parenting behaviour or technique. The following data is presented for the entire experimental group as no significant group differences were noted throughout this analysis (refer Table 15).

Table 15

Experimental Group Average Scores for Parent Responsibility Factor over Programme and Follow-up.

	Baseline	Midpoint	Endpoint	Follow-up1	Follow-up 2
Entire group	31.4	32.1	32.1	29.4	31.7

At baseline, the experimental group had an average score of 31.4 (range 22-39) which indicated that they fell within the mid-range and did not hold themselves or their child fully responsible for child behaviour. At the programme midpoint and post-programme, the group average was 32.1 with scores ranging from 28-38 at midpoint and 24-39 at programme endpoint. At both stages, the tendency for individual participant scores to increase slightly indicated that they moved towards heightened belief in parent-responsibility factors. At short-term follow-up, average figures dropped slightly below baseline figures but rose again at long-term follow-up. At no point throughout the programme or follow-up were the parent responsibility scores significantly different from baseline (t=n.s; $p>0.05$), therefore parent responsibility scores remained stable.

The mean for the group of parents who reported parenting difficulties in the literature accompanying the PLOC was 32.6 and 30.4 for those not reporting difficulties. The experimental group average varied within these means. In conclusion therefore, the programme did not appear to affect parent responsibility beliefs.

Child Control

The factor 'child control', measures the parent's belief of how much the child controls (or dominates) the parent's life. Seven statements for this factor produced a possible range of 7-35 with the higher scores indicating the feeling that the parent's life is largely controlled by the child. Effects on parent's life is measured by considering factors such as how many friends the parent has and the parent's ability to function independently of the child. The following data is presented for the entire experimental group as no significant group differences were noted throughout this analysis (refer Table 16).

Table 16

Group Averages for Child Control over the Programme and Follow-up.

	Baseline	Midpoint	Endpoint	Follow-up1	Follow-up2
Total group	15.0	16.1	14.1	13.3*	16.2

Note. * n=8.

At baseline, the entire experimental group obtained an average of 15.0 (range 9-21) which placed participants at the lower end of the scale and indicated that they did not feel their lives were controlled by their children. At programme midpoint, the experimental group obtained an average score of 16.1 with a range of 8-25. Three Group Two participants scored above the range midpoint (i.e., greater than 21) which indicated that they felt their child was increasingly controlling their (the parent's) life. This was reflected by the slight increase in group averages although no significant differences were noted between the two groups.

At programme-end, the average group score had reduced to 14.1 (range 7-20) and dropped further at follow-up to 13.3 (range 7-25) indicating a reduced belief that children were controlling the parent's lives. Interestingly at long-term follow-up, four participants recorded scores above the midpoint which pushed the group average to its highest level at 16.2 (range 7-24). The rise in child control issues at long-term follow-up may have been an artefact of a long period of time out of the course, the absence of a group support structure and a tendency to revert to baseline beliefs. However, the group average score was still well below midpoint (i.e., 21) indicating continued belief that children did not generally control parents lives.

In summary, the experimental group average fluctuated over the course of the programme and follow-up however, no significant differences were noted in scores compared with baseline data. These results indicate that child control beliefs were relatively stable although the relative drop in group means over the course indicates that parents were increasingly less likely to believe that their child controlled their life. Note that this was also the observation at the start of the course.

Parent Control

Parental control is the belief expressed by parents that they have control over their child's behaviour. Ten statements make up this factor with a possible score range of 10-50. Higher scores indicate a belief of minimal control over child behaviour.

At baseline, the entire experimental group had an average of 35.7 (range 24-46) indicating a tendency to believe they had little control over their child's behaviour (refer Table 17). There were no significant differences between the two groups at baseline (t = n.s, p> 0.05). A significant decrease in the average group score (32.4) at programme midpoint indicated a strengthening belief in parental ability to control child behaviour (t=4.04; p< 0.05). A comparison of group data at this point revealed that Group One scores were significantly different from baseline (t_{group1} = 4.43, p< 0.05) whereas Group Two scores did not show a significant change (t = n.s; p> 0.05). At programme end, a further significant decrease in the entire experimental group average (29.4) was again evident (t = 2.56, p< 0.05) and this time both Group One and Group Two produced significant results (t_{group1} = 3.5, $t_{group\ 2}$= 3.5; p< 0.05) indicating improvement in belief about own ability in controlling child behaviour.

Table 17

Group Average Scores for Parent Control Factor over Programme and Follow-up.

	Baseline	Midpoint	Endpoint	Follow-up1	Follow-up2
Group 1	33.6	30.0[s]	28.0[s]	32.5*	30.0
Group 2	38.0	34.8	30.8[s]	32.8*	34.2
Total group	35.7	32.4[s]	29.4[s]	32.6	32.1[s]

Note. S= significant result compared with baseline results (p<0.05). *n=4.

No further group differences were noted over the remainder of the course and follow-up period but long-term follow-up results did show that the entire experimental group average (32.1) remained significantly improved compared with baseline figures (t = 3.22, p<0.05). These results are encouraging as they indicate that the course contributed to an improvement in belief about parents own ability to positively

control child behaviour and that this improvement showed temporal stability (i.e., remained evident over time).

Summary

Overall, significant changes were noted in parental efficacy and parent-control domains over the course of the programme and follow-up. Group One participants experienced significant improvements in parent efficacy at the programme midpoint and these results were maintained to programme end but had reverted to baseline levels at follow-up.

The parent-control factor produced significant changes over the entire experimental group beginning at programme midpoint (i.e., four weeks into the programme). Both groups experienced significant improvement in their own belief about control over their child's behaviour. Group One gained significant results at programme midpoint and Group Two at programme endpoint. These improvements were maintained over time. Given the step-wise improvement in parent-control gains, one may consider that improvements followed the introduction of the applied behaviour analysis component of the programme. While this idea may have some validity, it remains a conjecture as conclusions about the contribution of programme components to changes in parental locus of control factors remain outside the scope of the current investigation.

Conclusion

Only the parent-control factor resulted in significant and enduring change over the course of the programme for both groups. Using group average data, group participants were considered to have positive parental efficacy prior to commencing the programme. They had a balanced view of responsibility for child behaviour and generally did not believe that their child controlled their lives. In contrast to these beliefs, participants initially reported (at baseline) that they believed they had little control over their child's behaviour. This belief showed a change in a positive direction over the course of the programme.

CHAPTER 7

Family Stress

The issue of family resources and stress is examined in this chapter. Using the Questionnaire of Resources and Stress – full scale (QRS - Holroyd, 1987), two major analyses were undertaken. First, individual scales were considered and summarised using the three major stressor groups (respondent issues, child issues and family issues) outlined in the QRS. This was done in order to determine the pattern or profile of stress associated with individuals in the experimental group.

The next section investigates the effect of the programme on the stress profiles within the experimental group. A consideration of individual stress response profiles follows in order to further our understanding of the change in stress associated with a child with an ASD over time and also to determine the effect (if any) of the programme on individual family stressors. The differential results between the two sample groups are discussed. The final section considers the study outcomes in the light of previous research and attempts to clarify the 'stress profile' of New Zealand parents with children with an ASD.

Programme Outcomes and Effects on Stress Profiles

Respondent Scales

The following seven scales pertain to issues concerning the respondent – in this case, the mother of each child.

Scale 1 - Poor health/mood. This scale reflects the parent's low mood, sadness, depression, tension, ill health and feelings of pressure from taking care of the child. It seems to relate to the respondents' *social role* as it pertains to the child with mothers who report role satisfaction in the roles of mother, carer and household duty management scoring lower than those who report role dissatisfaction (Holroyd,

1987). Mothers who do not work outside the home have also been found to have lower scores than those who do work outside the home (Trivette & Dunst, as cited in Holroyd, 1987). Japanese mothers of children with an ASD and children with speech or behaviour problems in the context of adequate intelligence have been found to have higher scores on this scale suggesting stress associated with discrepancies or inconsistencies between developmental expectations and child behaviour/s (Inanami, Nishi, & Ogura, 1980; Murphy, 1980 as cited in Holroyd, 1987). Scale 1 elevations reflect an interaction between the child's condition (ASD) and parental expectation of what 'should be'. The severity of the condition alone has not been found to be a significant predictor of poor health/mood scores (Holroyd, 1987).

At baseline, 40% of participants reported significantly elevated scores on Scale 1. Interestingly, all were members of Group Two (see later section for comment). At the end of the programme, 50% of respondents had significant elevations on Scale 1 but at follow-up, this figure had reduced again to 40% of respondents. Thus, less than half of the experimental group reported role dissatisfaction or had difficulties reconciling their child's condition and their own expectations.

Scale 2 - Excess time demands. This scale includes items that seek to determine how much time the respondent is able to spend engaging in activities outside the home, visiting friends and partaking in non-care related activities. As expected, this scale has been found to have a negative correlation with child age in populations of normal and chronically medically ill children indicating that young children generally require the parent to spend more time in direct care activities. However, this does not appear to be the case with the child with intellectual difficulties. In this population, increasing age does not release the mother from excessive responsibility and significant direct care is required over the child's life span. High scores on this scale have been associated with non-availability of support systems, low finances, low role satisfaction for the mother and increased child behaviour issues and severity of the condition.

At baseline, 40% of participants reported significantly elevated scores on Scale 2. This figure remained basically consistent over the period of the programme and follow-up indicating that less than half of the respondents had significant stress caused by perceived excess time demands.

Scale 3 - Negative attitude towards the child/over-sensitivity to the child's condition. The scale title in this case is somewhat of a misnomer. It does not reflect the views of the respondent *towards the child,* but rather it reflects the social sensitivity of the respondent in terms of how they perceive others think of/react to their child and themselves as the parent of the child. In addition, the scale also reflects the respondent's worries for the child in terms of optimal future functioning and acceptance by the community. By inference, this scale suggests the respondent values relationships with others combined with a tendency to be worried or fearful of the assumed reactions/thoughts of others toward the child or themselves. Fears for the child's future are also manifest in concerns about the potential functioning of the child and future expectations.

Many studies suggest higher scores on this scale are related to the degree of severity of the child's condition. Mothers of children with an ASD have been found to have higher scores than parents of children with other disabilities including intellectual deficits or physical disorders (e.g., blindness and cerebral palsy - Holroyd & McArthur, 1976; Inanami et al., 1980).

At baseline, 80% of participants within the experimental group reported elevated scores on Scale 3. While this figure fell slightly during the course of the programme, it remained considerably elevated at long-term follow-up. This indicates that the majority of respondents had significant concerns over the social reaction to the child and future community acceptance of the child.

Scale 4 - Overprotection/dependency. This scale reflects the degree to which the child is dependent on assistance from the respondent (and others) and is perhaps over-protected by the respondent (and/or others). This scale was originally included

in the belief that it would indicate the degree to which respondents would over-protect or create dependency in their child. However, strong relationships noted between this scale and conditions like ASD (Holroyd & McArthur, 1976; Inanami et al., 1980) and intellectual disabilites (Wilton & Renaut, 1986), have led researchers to the belief that this scale is more interactional in nature. Thus, elevated scores are partly attributable to child disability/condition characteristics *as well as* parent attitudes or behaviours (Holroyd, 1987).

At baseline, only 30% of respondents had elevated scores on Scale 4 and this figure dropped to 10% at programme end indicating support for the programme in lowering overprotection/dependency issues. This finding is consistent with another study which suggested supportive education could lower the stress associated with these issues (Brown, 1977 as cited in Holroyd, 1987). Long-term follow-up results showed maintenance of the reduced scores (the remaining participant had a severely affected child). However, following the advent of multiple family stressors, one further participant reached a significant level on this scale after the programme was concluded.

Scale 5 - Lack of social support. This scale reflects lack of organisational resources in the community or a lack of family involvement/non-access to available resources, lack of supportive friendships and family disagreements over care-taking tasks. Of particular note for the social support scale is the *perception* of availability of resources in the community and this has been found to be a consistent stressor across cultures (Kodaki & Inanami, 1978).

The significance of this factor has had variable results in previous research. For example, Bristol (1979 as cited in Holroyd, 1987) did not find lack of social support to be a significant factor for families with children with autism, whereas others have found the opposite (e.g., Holroyd et al., 1975). A New Zealand normative sample (Wilton, 1986 as cited in Holroyd, 1987) indicated that lack of social support was a significant factor among families with children with a range of difficulties including early infantile autism. In the experimental group, 70% of participants indicated a lack

of social support was a significant stressor at baseline. During the programme and follow-up periods this figure fell slightly but remained significant for 60% of participants.

Scale 6 – Over-commitment/martyrdom. This scale is (as the name suggests), concerned with the intensity of involvement of the respondent with the child. It implies that the respondents with a high score consider themself solely essential to the care of the child. The score does not seem to reflect the *actual* amount of care provided or required. Mothers do not score higher than fathers (Holroyd et al., 1975) and scores do not relate to the mother's age, education, number of children or father's education (Murphy, 1980 as cited in Holroyd, 1987). Scores may decrease as the child ages which is not surprising when considering the high dependency of infants and young children.

Low internal consistency for this scale suggests items are measuring different domains e.g., sense of worth derived from caring for the child or worry about the future when the respondent can no longer care for the child. Results of previous studies have also been variable. For instance, Inanami et al., (1980) found zero or negative correlations among families with children with developmental disorders while Bristol (1979 as cited in Holroyd, 1987) found this scale could differentiate between normal and autistic populations. In this study, 40% of the experimental group had elevated scores on this scale at baseline and over the course of the programme/follow-up indicating that respondents did not generally consider themselves solely responsible for their child's well-being. Due to the fact that this figure did not represent a majority proportion of the experimental group and due to the low internal consistency of the scale, attempts to interpret the results are not considered a priority here.

Scale 7 – Pessimism. The items on this scale reflect an *expectation* that the child's condition will worsen, that the respondent and family will become increasingly burdened in the future and the degree to which non-participatory care (institutionalisation) outside the home is considered. Some studies have found that

this scale score generally increases as the child ages (including within the normal population), however no such relationship was discovered among children/adults with autism (Holroyd, Brown, Wikler, & Simmons, 1975). As expected, this scale has been found to be significantly elevated among those families with children with life-threatening or terminal conditions, however within *these* families where *expectations* of prognosis are clear (even if negative), respondents have been found to have lower pessimism scores (Holroyd & Guthrie, 1979).

At baseline and at the end of the follow-up period, only one participant had an elevated pessimism profile. These results indicate that this was not a significant concern among the experimental group. There are a number of possible reasons for this outcome as will be discussed in the next section.

Summary of Results and Discussion of Personal Problems for Respondent Scales

Analysis of the results of the respondent scales among the experimental group showed that the majority of participants recorded high scores on negative attitude/over-sensitivity to disability and lack of social support scales. It is proposed that there could be some interactional overlap between these two stressors.

In contrast to children who can be easily visually assessed as being 'physically disabled', the child with ASD often appears 'normal' and frequently is notably physically attractive. Contrary to some conditions (e.g., Downs Syndrome), the average observer has limited or no knowledge of the features of ASD. Errant social behaviour, speech or mannerisms are not generally expected when interacting with or observing a child. Observing behaviours dissonant with expectations can lead to various attempts to rationalise events and these cognitive attempts can result in various reactions (often negative). Not only are these reactions aimed at the child but the parent may also bear the brunt of negative reactions (or perceived negative judgements/actions). Accordingly, parents can easily become sensitive to the reactions of observers. In a cyclical fashion, heightened vigilance of parents to the child's social interactions with others requires some expectation of potential negative

outcomes. A number of the actions/behaviours displayed by the child with an ASD are anti-social or at best non-interactive, thus parental sensitivity or awareness of the reactions (or perception of reactions) of others is reinforced.

Regardless of how it arose, this heightened sensitivity to the child's behaviour and the reactions/judgements of others is a constant factor (O'Moore, 1978). Parents are well aware that a number of these behaviours are non-rewarding and parents often report not being able to 'let down their guard' when with the child and others. Moreover, they feel that they cannot impose on family or friends for fear they will lose the support of others due to the variety, severity and nature of behaviours associated with this chronic condition. In many situations these concerns alone account for the parents choosing not to participate in social situations. This in turn is proposed to be instrumental in the second significant profile - a perceived lack of social support. In this case, the parent may well be aware of support structures but may feel unable to access them due to child behaviour factors as opposed to the support structures being unavailable or inaccessible per se. These observations were supported by the general comments of research participants throughout the course of the study and to some extent by the composition of the scale items.

The ten items for the lack of social support include some items which clearly indicate at least some access to specific services. For example,

> Q85 "I belong to organisations which help with problems I have with _____."
>
> Q165 "There is an organisation for families who share our problems."

Responding positively to these two items accounts for 40% of the final score (where a significant profile is based on 5/10 agree answers). Similarly,

> Q107 "The doctor sees _____ at least once a year".

(an expected occurrence in New Zealand) and

> Q78 "Many people simply don't understand what it is like to live with _____".

(a common response from parents as a result of the range of difficulties, variance and lack of knowledge of the condition of ASD) quickly and easily raises the score to 4/10 affirmative answers with only one more affirmative answer being required to take the scale to 'significant' status. While this may signal a general caution about the interpretation of such scales, the QRS has been found to have reliability and validity (Holroyd, 1987) and factor analysis has indicated that the fifteen scales included in the full version of the questionnaire are valuable.

Other scales in the respondent problem section affected less than half of the participants at any particular stage and will not be discussed here. Of more significance is the lack of pessimism shown as a stressor for parent participants. Many participants were well aware that their child's condition was chronic and life-long. Consistent with previous studies (e,g, Koegel et al., 1992), many expressed their concern/fear for the future care of their child as they aged. However, despite these concerns, the vast majority of these participants were positive about their child, his/her condition and their own/the family's direction. Certainly the current New Zealand mental health environment supports family and community 'inclusion' over institution-based care and this option did not enter discussions with parent participants regardless of the level of concerns about the future. Many parents were motivated to join the research group specifically to attempt to develop future strategies to manage their child's behaviour and help them to move their child towards independence or at least help their child access organisations/individuals that could assist with future functioning.

Perhaps the lack of pessimism found among the experimental group was a consequence of the type of parents seeking assistance but it is still somewhat surprising given the lack of knowledge about prognosis for the individual child and the huge variance of ability/functioning level within the spectrum of disorders

associated with ASD. The result found in this study was consistent with other research within populations with ASD which also found that stress associated with pessimism was not significant (e.g., Bristol, 1979 as cited in Holroyd, 1987).

Family Problem Scales

The following three scales pertain to issues concerning the *family* of the child.

Scale 8 - Lack of family integration. The items on this scale are concerned with disharmony between family members, lack of intrafamilial support, family pathology, an inability to include the child in family activities and the presence of an atmosphere of rejection towards the child. This is one of two scales on which parents of children with emotional disorders score higher than parents of children with a life threatening disease (Holroyd & Guthrie, 1979). However the elevation of this scale does not clearly address the direction of the relationship between stress and family integration. For example, family disharmony may be responsible for increased stress in child management, alternatively, the burden of caring for the child may cause or exacerbate family disharmony. Then again, perhaps both factors could account for some family stress in a bidirectional or interactional manner.

At baseline, this scale was elevated for only one participant who subsequently went through an acrimonious separation process. Two further participants reported elevated scale scores post-programme and both also underwent family break-ups. All these participants reported family problems were present before the course began and were part of a process over the passage of time. Two thirds of these participants reported at least part of the irreconcilable problems in their relationships with their partners were due to the decisions and care involved in living with an individual with an ASD. Scores for these participants remained elevated at long-term follow-up.

Scale 9 - Limits on family opportunities. Items on this scale pertain to family members having to forego opportunities for employment, education, social activities and/or personal growth. This scale is basically independent of age or disability of the child but does relate to family income, role satisfaction and the ability of the family to meet the needs of the child and/or respondent.

At baseline, fifty percent of participants had elevated profiles on this scale. This figure fell over the course of the programme and follow-up to 40% of participants. It is believed that the programme contributed to increased role satisfaction as participants gained skills in successful behaviour management techniques and were able to confidently integrate the child into social activities. At the beginning of the programme, two participants were involved in community activities and by programme end, a further five participants had become involved in activities directly related to the knowledge or confidence gained during the course. This involvement could mitigate against a lack of opportunities for involvement in areas which extend personal growth for instance, and while not necessarily in paid employment, nevertheless added a new role and skills to the respondent's repertoire.

Scale 10 - Financial problems. The items on this scale pertain to the adequacy of income, housing and cost of care for the child. It is not correlated with the age of the child but is generally elevated for populations in which a physical disability is present due to structural modifications of dwellings and physical apparatus required. Not surprisingly, families facing financial hardship are more likely to experience stress regardless of the physical or intellectual condition of their child. In some studies of families raising children with an ASD, mother's age and education level have been found to be positively correlated with financial stress (Holroyd et al., 1975; Murphy, 1980 as cited in Holroyd, 1987) although this is not always the case (Inanami et al., 1980).

This scale can tentatively be utilised to determine socio-economic status with the assumption that those participants who report no financial difficulties are in a higher socio-economic group compared with those who do report difficulties. However, this scale also goes beyond these assumptions to consider the stress associated with finances whether perceived to be adequate or not. A simple consideration of family income would not provide this sort of information and it would be presumptive and pre-emptive to make conclusions based on purely material matters.

At baseline, 40% of participants reported significant financial stress although this decreased throughout the course and follow-up to end at 10% of participants. By long-

term follow-up, of the two participants who registered elevated scales, one had undergone a family separation and the other was coping with a difficult financial situation which had been apparent before the course began. The remaining elevated scales at baseline reflect variation in self-employment and sole care-giver circumstances which were no longer problematic post-programme.

Summary of Family Problem Stressors

Analysis of the results of the experimental group stress profiles showed no general family problem stressors. Half of the participants felt limitations existed in family opportunities prior to the course but this figure dropped to 30-40% of participants during the programme and follow-up. Forty percent of participants showed elevated financial stressors at baseline but half of these could be attributed to expected fluctuations given the employment and living situations of some participants and were not consistent stressors over time.

An increase in stress as measured by the lack of family integration scale over the course of the programme and follow-up reflects the observation that some participants (who considered their family situations to be difficult prior to the programme) terminated their relationships during the nine month period over which the study operated. When questioned about these outcomes, the participants reported that the passage of time was a more significant factor in family breakdown than either the programme or the extra demands of the child's condition although the latter factor did contribute at least indirectly to two of these outcomes.

Problems of Individual/Child Scales

The following five scales pertain to child issues.

Scale 11 - Physical incapacitation. This scale pertains to the child's health, use of specific aids, ability to take care of his/her own physical needs and capability for participation in sport or outings. As expected, there is a significant negative correlation between scores and age suggesting care with interpretation of results where the child is very young. Obviously higher scores are noted from respondents

who care for individuals with physical needs, however intellectual disabilities also are associated with higher scores compared with normal control populations (Koegel et al., 1992).

Studies examining populations containing children with an ASD have found higher scores on this scale when compared with intellectually or emotionally disturbed children (Holroyd & McArthur, 1976) and higher scores with mothers with low education levels (Inanami et al., 1980). Among the experimental group, two participants (20%) had elevated profiles at baseline and this increased to 30% during the course and period of follow-up.

Two of the latter cases were parents of preschoolers who may have recorded elevated profiles due to age factors. It is unclear why these factors were not evident at baseline apart from the added social context of both children moving into the early childhood education environment and therefore being exposed to more opportunities for social interaction. Of the remaining two respondents, one child had ongoing health issues separate from the condition of ASD for which intensive medical investigation coincided with the programme/follow-up period. The remaining child was severely affected by ASD and non-verbal. He did not possess basic self-care skills and was unable to participate independently in normal sports or social activities.

Scale 12 - Lack of activities for the child. This scale focuses on the provision of activities/objects to keep the child active and entertained. Populations containing individuals with an ASD have been found to have significant elevations on this scale compared with individuals with Downs Syndrome, intellectual impairment, physical disabilities and normal control groups (Holroyd & McArthur, 1976; Inanami et al., 1980). Correlations with age are significant among individuals with developmental disabilities indicating increased lack of activities as the child ages. While there is evidence that this scale is culturally sensitive, no cultural differences were noted between Japanese and American respondents with children with ASD (Kodaki & Inanami, 1978).

At baseline, 40% of respondents had elevated stress profiles for this scale, however this figure dropped consistently during the programme and follow-up periods to end on 20%. It is proposed that as parent understanding increased and errant child behaviour decreased, children were more able to assimilate into both family and individual activities.

Scale 13 - Occupational limitations for the child. As the participants in this study were all aged 10 years or below, this scale reflected parent's current views on educational opportunities and more relevantly perhaps, concerns about the future employability of their child. In some ways, this scale encapsulated the parents' feeling of 'hope' or potential for their child's working future.

Previous studies have shown that parents of children with ASD have more concerns than parents of children with Downs Syndrome (Holroyd & McArthur, 1976). Koegel et al., (1992), suggested that level of *current* functioning/involvement was more important than physical or intellectual disability per se and concerns were heightened if the condition was more disabling when the child was young (Holroyd & Guthrie, 1986).

This scale was significantly elevated for 60% of the experimental group at baseline. While a drop was noted at programme end (40%), long-term follow-up results showed a return to baseline levels which indicates support for the findings noted above. A closer examination of the items in this scale however, reveals similar issues to those noted in scale 5 (lack of social support). For example, most parents receive the 'handicapped child allowance' through the New Zealand health system or 'Ongoing and Reviewable Resourcing Schemes' (ORRS) funding through the NZ education system and therefore would answer affirmatively to the statement;

Q197 "We get special funds because of _____'s problem".

The provision of educational funding also allows teacher aide or specialist service intervention on a regular basis and therefore affirmations could also be expected for the statement:

Q53 "A counsellor or teacher sees _____ at least once a month".

Two affirmative answers places the respondent at the significance level for this scale and neither statement directly addresses the concerns inherent in the scale title; employment opportunities.

These issues aside, many parents cited concerns about the future employability and educational opportunities available to their child at baseline interviews. In particular they expressed concerns that their child would not receive appropriate educational opportunities due to current disruptive behaviours, learning styles not catered for in most school systems and/or a general lack of understanding of the ASD condition among teaching staff. The temporary drop in concerns at post-programme is proposed to reflect the alleviation of errant behaviours and increased confidence in the parents own and their child's abilities. The rise at long-term follow-up could equally be attributed to future educational or employment concerns separate from those that caused elevated profiles at baseline reflecting an attitudinal shift for parents who are nonetheless still concerned for their child's future employment potential.

Scale 14 - Social obtrusiveness. Items on this scale relate to both the child's inappropriate behaviours and the respondent's sensitivity to community opinion. Mothers score higher than fathers on this scale perhaps due to being the primary caregiver (Holroyd, 1974). The relationship between the child's behaviour and concerns about social acceptability appears to be mediated by the (mother's) perception that their child *is* socially obtrusive and perhaps more difficult to assimilate into society.

At baseline, 80% of respondents had significantly elevated profiles on this scale, however this had dropped slightly by the end of the long-term follow-up period. Generally parents of children with ASD felt that they could not relax in social settings due to the potential or actual behaviour of their child. They felt that they must protect their child from the remarks of others and that the community as a whole was unused to children with ASD. The overlap between the results of this scale and the perception

of social obtrusiveness and the significant elevations on scale 3: respondent sensitivity to the reactions of others, is noted.

Scale 15 - Difficult personality characteristics. This is the longest scale on the QRS and has excellent internal consistency. Basically this scale measures the child's 'personality' problems including cognitive, psychiatric and informational deficits and behavioural problems. Thus it is one of two scales (the other being lack of family integration) on which parents with children with emotional disorders score higher than parents with life-threatening or terminal illness. Family stress is directly related to scores on this scale and is proportional to the level of role dissatisfaction expressed by the mother (Trivette & Dunst, as cited in Holroyd, 1987). Parent scores have been found to be negatively correlated with the amount of social support received and scores decrease as the child ages unless the condition involves intellectual impairment.

This scale was significantly elevated for 100% of the respondents at baseline. The core triad of ASD; communication, socialisation and interest issues as well as behaviour management and independence problems are reflected in the high scores of respondents. Post-programme, 80% of respondents continued to show elevations on this scale and this figure continued to decline slowly over follow-up to end at 70% of respondents displaying elevated profiles.

Does this decrease reflect an actual improvement in the condition of the child or a change in the perceptions/beliefs of the parent? Perhaps both factors were relevant. For example, in two cases the respondent's children made significant behavioural gains placing them both at an age-equivalent level in at least 2/3 adaptive living skill areas. In these cases, not only did the child approach 'normal' functioning in at least some behaviours, but the parents also recognised these advances and expressed satisfaction in both their child's attainments and their own increased proficiency and diligence in helping their child change their behaviour or reach new goals.

Summary of Individual/Child Scale Results

Analysis of the results of the experimental group stress profiles for individual/child stressors showed that all participants felt stress due to the difficult characteristics associated with the condition of ASD. Seventy percent of respondents continued to show elevated profiles at long-term follow-up which reflects the enduring nature of the disorder. However, given this enduring nature of ASD, it was perhaps more significant that the remaining respondents no longer felt that this was a particular concern at follow-up. Indeed, at least two of these respondents had watched their child accelerate in terms of adaptive skill acquisition and elimination of disruptive behaviour during the course of the study. The agent and direction of change for these results remains unclear as noted previously.

The majority of respondents (80%) also noted concern over the 'socially obtrusive' nature of their child's behaviour although the number of respondents who found this feature stressful also dropped over the course of the programme. A further drop was noted in stress related to 'lack of activities' for the child over the course of the programme and follow-up. These results suggest that some individual/child characteristics were mitigated during the course of the study and could be attributed to programme content. There were no changes noted for the 60% of respondents who had concerns about the educational and long-term occupational needs/potential of their child but as noted, the concerns at follow-up may have been qualitatively different from those expressed at baseline. Physical incapacitation was not of significant concern to the majority of the experimental group.

General Comment on the Impact of the Programme to the Experimental Group Stress Profiles

Most reductions in the number of elevated stress profiles occurred in those profiles associated with individual or family characteristics. Relatively little improvement was noted in the respondent scales by comparison. This general finding suggests that respondent attitudes, perceptions and beliefs about their own role, care demands and perceived support systems remained relatively resistant to change over the programme

and beyond. In contrast, respondents noted improvements (decreased stress) in areas concerning child and condition (ASD) characteristics and activities able to be accessed by the child as well as stressors affecting the family - most notably increases in family opportunities and decreases in financial stress. This final improvement is not suggested to be due solely to the programme as each situation was assessed to be due to unique individual and family circumstances.

In summary, the programme shows some utility in relieving respondent stress associated with child and family difficulties but does not appear to alleviate respondent stress about their own role and demands placed on them.

Some of the questions raised during the examination of individual profiles become pertinent here. For instance, how is it that child characteristics may be improved to the point that respondents no longer find them a source of stress and yet their own interactions, perceived roles and interdependence on the child remain unchanged? An examination of some of the elevated respondent profiles may shed some light on this query. For instance, alleviations of child stressors could be expected to positively alleviate overprotection/dependency issues and indeed this latter profile (while not significant for the majority of respondents) did show some improvement over the course of the programme. Respondent scales which reflected no or little change e.g., social support, over-commitment/martyrdom, negative attitudes towards the child/condition showed little relation to child issues and instead tended to reflect respondent views about their perceived relationships with others and lack of access to community resources (social support), their beliefs about their own critical role in being able to provide care for the child (over-commitment/martyrdom) and a continued sensitivity to the reactions/judgements of others (negative attitudes towards child/condition).

Little or no change in the poor health/mood scale reflects a continued depression of some respondents concerning their views about their role in relation to their child and the child's condition. It is interesting to note that only one of the four respondents with elevated poor health/mood profiles had a significant health concern. Of the remaining three respondents with elevated health/mood profiles, all reported poor

emotional health and these three participants also clearly had the highest number of elevated stress profiles compared with other participants throughout the period of the study. The average number of elevated profiles among those respondents who did not have health/mood concerns or significant physical health issues was 5.1 at baseline and 2.8 at follow-up compared with 11.3 at baseline and 11.6 at follow-up for those who did have elevated health stress profiles. The differences between these results is considerable and has implications for child behaviour change outcomes. In hindsight, these three latter participants may have benefited from direct intervention aimed at alleviating emotional stress before attempting to change child behaviour. Yet, it must be noted that all child participants still made considerable behavioural gains despite parent-participants' reports of poor health/mood. Perhaps though, child behavioural gains could have been enhanced by this modification and it would be recommended in future administration of the programme.

One other scale which showed no change over the course of the study was 'excess time demands'. One would expect that alleviation of child behaviour issues and increased adaptive behaviour skills would lead to less time having to be spent in direct care duties and an overall decrease in caregiver time demands would not be unexpected. As noted in the discussion of results for this scale, elevated scores have been associated with non-availability of support systems, low finances, child characteristics and role satisfaction of the mother. While child behaviour improved over the course of the programme for all participants, individual analysis of results here reveal some interesting points.

Firstly, two of the four participants who had high time demands at follow-up had the two children who were least verbal and most difficult in terms of behaviour. Behavioural improvements would therefore not necessarily lead to significant decreases in time demand stressors compared with other child-participants. The level of verbal functioning in both cases complicated behavioural management. Behavioural improvements, while apparent, were more likely to be replaced by other problem behaviours. Secondly, all four respondents had significant family issues to contend with, unrelated to the target child, and all reported significant stress in terms

of lack of social support. Three of these respondents also reported poor health/mood and low role satisfaction. Financial stress affected only those two participants who underwent family break-downs. In conclusion therefore, elevated stress in terms of excess time demands while pertinent for only 40% of respondents, can be explained by reference to factors largely unrelated to child behaviour or improvement in child characteristics.

Individual Changes in Stress Profiles

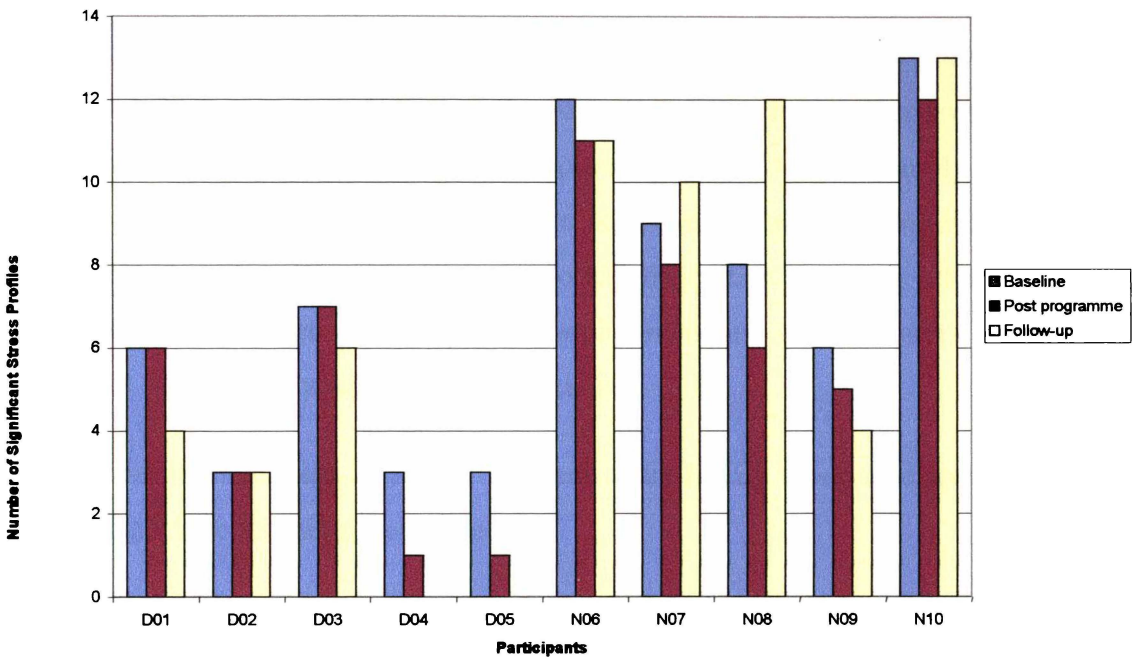


Figure 19. Changes in stress profiles over the course of the programme and follow-up.

Figure 19 shows changes in the number of elevated stress profiles per respondent. At baseline, respondents had elevations ranging from 3-13 profiles out of a total of 15 with an average overall figure of seven elevated profiles per respondent. There was a significant difference between the average number of elevated profiles per group ($t = 3.34$, $p<0.05$) indicating that Group Two participants were reporting more stress at baseline. There was a significant decrease in the number of elevated profiles between baseline and programme end ($t = 3.875$, $p<0.05$) for the entire experimental group. No further significant decreases were noted between baseline and long-term follow-up or

between programme-end and follow-up (t = n.s, $p>0.05$) indicating that statistically significant changes (improvement in stressors) were achieved only during the programme. Differences between Group One and Group Two data remained significant at both programme end ($t = 2.59$, $p<0.05$) and long-term follow-up ($t = 3.23$, $p<0.05$) indicating that Group Two continued to show more elevated profiles compared with Group One at each stage. The next section will briefly consider each individual response in terms of elevated stress profiles at each stage of the study.

Group One (ABA – ToM)

Damon (D01). At baseline, Damon's mother recorded six elevated profiles. In the respondent domain, elevated scales reflected a sensitivity to the negative attitudes of others (which may have also contributed to elevations on the over-protectiveness scale) and a lack of approach to social support systems. Damon's family lived in a rural area with limited availability/access to organisations aimed at individual's with an ASD. At baseline, Damon's mother reported difficulties accessing school support and some disagreements with extended family members over Damon's behaviour which had lasting family relationship implications.

There were no indications of family problems. The family functioned well as a unit and no financial constraints were noted.

Three elevated profiles in the individual domain, difficult personality characteristics, social obtrusive behaviour and a lack of activities, reflected the difficult behaviours and restricted range of activities inherent within the ASD condition.

At programme end, five of the six original scales remained significantly elevated but over-protection/dependency was no longer significant. It was replaced by poor health/mood associated with the mother's ongoing medical condition. This scale did not appear elevated at baseline although the medical condition was chronic. It is proposed that other concerns (for example, the care involved in raising Damon) left little time to consider one's own health issues. Damon's mother may also have felt that Damon's needs were superior to her own. As Damon's behaviour improved over the programme, it is suggested that she was able to consider her own needs and thus the

health issues came to the forefront. A consideration of individual items on this scale showed concerns were associated with a general sadness about Damon and a concern for his long-term future.

Interestingly, at long-term follow-up, poor health/mood was no longer significant. Damon's mother began a local support group for other community members subsequent to the programme and reported increased satisfaction in both helping others and in her own confidence in being able to effectively care for and manage Damon's behaviours. By the end of the follow-up period, the six original elevated profiles had been reduced to four. A sensitivity to the attitudes of others and a lack of access/availability to social support systems continued to be significant respondent issues while the remaining two profiles related to child concerns; occupational limitations (which reflected a change in concern from current behaviour and functioning to long-term/future occupational or educational potential) and the socially obtrusive nature of Damon's behaviour.

Fern (D02). At baseline, Fern's mother rated three significant profiles. Two (negative attitudes and over-protectiveness/dependency) showed a co-relationship similar to that noted for Damon above i.e., a sensitivity to the attitudes of others may increase protectiveness of the child. As noted in the scale description section, elevated scores on this profile have been found to have more association with the nature of the ASD condition as opposed to a tendency for the parent to overprotect the child per se. This is supported by the third elevated profile: difficult personality characteristics.

At programme end, over-protectiveness/dependency was no longer significant but was replaced by a concern over physical incapacitation - particularly a concern over Fern's ability to take care of her own needs and participate in outings etc. There is a significant negative correlation between the child's age and this scale noted in the research, however as it was not considered problematic at baseline, it is proposed that these concerns arose as a result of Fern starting preschool. The other two profiles remained significant at this point and these three profiles remained consistent throughout the remainder of the programme.

Piripi (D03). Piripi's mother reported seven significant profiles at baseline. Three scales related to respondent issues: sensitivity to the attitudes of others, a lack of availability/access to social support systems and excess time demands. Piripi was the eldest of three children aged 2-5 years. Piripi's father worked outside the Waikato region and his mother worked part-time. The family did not have extended family assistance available within the Waikato region. Piripi's level of functioning also placed him within the more severe range of ASD with limited verbal abilities and very difficult non-social behaviours as reflected by the three elevated scales within the child concern domain: difficult personality characteristics, socially obtrusive behaviour and concerns over future employment and educational opportunities. There was a significant family issue (limits on family opportunities), which reflected the difficulties inherent in caring for Piripi and his young siblings.

These stressors remained significant at programme end and follow-up apart from the loss of significance for the family issue at long-term follow-up. At this stage, the family shifted outside the Waikato region for employment and family reasons. Piripi's father no longer had to travel vast distances each day and while his mother engaged in further work, whanau support was available. While improvements in Piripi's behaviour and increases in his mother's parenting confidence were considered to have contributed to increased participation in family activities, the shift of the family into a cultural context that embraced the child/person and accentuated family and community inclusion could also have been at least as important in maintaining the behavioural gains noted throughout the programme.

Hugh (D04). Hugh's mother reported three elevated scales at baseline. Two (difficult personality characteristics and socially obtrusive behaviour) referred to difficulties inherent within the condition of ASD. The other elevated profile concerned financial stressors (due to the family living situation) which was reduced during the course of the programme.

At programme end, only one scale (social obtrusive behaviour) remained significant and by long-term follow-up, no stress profiles reached significance.

Flynn (D05). At baseline, Flynn's mother reported three significant stressors; difficult personality characteristics and socially obtrusive behaviour (as consistent with the condition of ASD) and future concerns over occupational and educational potential. At programme end, only one scale (socially obtrusive behaviour) remained significant and at long-term follow-up, no significant profiles remained.

Summary of Group One Individual Results

At baseline, all parent participants had significant concerns about features associated with their child's ASD. Difficult personality characteristics were problematic in all cases and the socially obtrusive nature of the behaviour was of concern to 4/5 participants. Fears or concerns over the child's future in educational or occupational endeavours were significant for two of the five participants. Family problems were not particularly evident with only one family reporting financial difficulties and one other reporting a lack of family opportunities. In terms of respondent issues, a sensitivity to the reactions of others (3/5) was accompanied by significant over-protection/dependence in two of the five cases and a lack of availability or access to social support systems was also of significant concern for two participants.

Immediately after the programme, the most notable drop in significant stressors occurred within the child problem domain - particularly on the difficult personality characteristic scale. Two of the five participants no longer felt characteristics associated with their child's condition were significant although there was no change in the number of participants who were concerned with socially obtrusive behaviour. Family issues continued to be fairly insignificant with only one participant noting concerns over family opportunities. Another notable drop occurred in the respondent section where both the participants who had significant ratings on the over-protection/dependency scale at baseline, no longer did so. This observation lends support to the suggestion by Brown (1977) that supportive education may lessen overdependence and or overprotection. Sensitivity to the reaction of others and a lack of availability/access to social support networks continued to be the key stressors in this group at this time.

Over the period of long-term follow-up, stressors continued to abate. With regards to child issues, two respondents each had elevated profiles for difficult personality characteristics, socially obtrusive behaviour and concerns about future occupational/educational opportunities - an average decrease of 41.6% from baseline figures. There were no significant family stressors noted at follow-up - a decrease of 100% from baseline. Respondents were most concerned by sensitivity to the reactions of others and a lack of availability/access to social support systems/organisations. No further changes in respondent issues were noted beyond programme-endpoint indicating an average decrease of 25% from baseline.

In conclusion, the programme appeared to have a marked effect in mitigating particular child difficulties/stressors - most notably difficult personality characteristics associated with ASD and the socially obtrusive nature of ASD behaviours. Parental concerns over future opportunities for their children were significant at times but were not consistent over particular individuals over time and therefore difficult to measure the effect of the programme against. Family stressors were not significant for this group so no conclusions about the effect of the programme can be determined. In terms of respondent issues, the programme appeared to have a significant impact on the level of over-protection/dependency reported but did not affect sensitivity to the (perceived) reactions of others nor did it alter the stress associated with a lack of access/availability to social support systems.

Two participants (40%) experienced a reduction in the number of significant stressors over the course of the programme and a total of four participants (80%) had a reduced number of significant profiles at long-term follow-up (compared with baseline and/or programme endpoint). No participants experienced an increase in the number of significant profiles over the course of the programme or follow-up and only one participant (10%) had the same number of elevated profiles throughout this period.

Group Two (ToM – ABA)

Kyle (N06). Kyle's mother reported 12 significantly elevated stress profiles at baseline. Four pertained to child issues; difficult personality characteristics, socially

obtrusive behaviour, lack of activities and future concerns over educational/occupational potential. As noted previously, all these difficulties are inherent within the condition of ASD. Family concerns included finances and a lack of family opportunities. Most notable however, were the 6/7 elevated profiles concerning respondent issues. Poor health/mood, excess time demands, a sensitivity to the attitudes of others, perceived lack of social support, a belief that she was the only one able to provide adequate support for Kyle and pessimism were all features of concern at baseline.

At programme-end, all *respondent* difficulties remained. A lack of family integration became significant as personal difficulties between Kyle's parents became apparent but the financial stressor disappeared due to natural fluctuations in the self-employment field. A lack of activities for Kyle was no longer a cause for concern among child issues but all other significant child issues remained unchanged.

No short term follow-up data were available for Kyle although the family difficulties were reconciled and the family moved premises subsequent to the programme. At long-term follow-up, 11 profiles were rated as significant. The lack of family integration issue became non-significant but a lack of activities for Kyle became a significant concern again. Overall, the range of profiles that were significant at long-term follow-up was relatively unchanged from those noted at baseline.

Bryan (N07). Bryan's mother recorded nine significant stress profiles at baseline. The child issues were the same as those noted for Kyle (difficult personality characteristics, socially obtrusive behaviour, lack of activities and concerns about future employment/educational opportunities). One family issue (lack of opportunities) was significant and the remaining four profiles related to respondent issues (poor health/mood, sensitivity to the attitudes/responses of others, lack of social support and over-commitment/martyrdom).

At the end of the programme, two scales were no longer significant (limits on family opportunities and poor health/mood) but a lack of family integration became significant. The parents in this family also faced relationship difficulties and some

respondent issues (e.g., lack of social support and over-commitment) are proposed to reflect these difficulties as the mother often became the sole caregiver and became increasingly unable to share parenting duties or access the level of support required to care for their child/ren.

These increased care-giving responsibilities are reflected in long-term follow-up profiles which showed an increase in the number of elevated scales in respondent and family issues (poor health/mood, excess time demands and increased limits on family opportunities). On the other hand, the number of elevated profiles concerning child issues diminished with the loss of 'lack of activities for the child' as a significant factor.

Eliam (N08). At baseline, Eliam's mother recorded eight elevated stress profiles. Three involved child characteristics (physical incapacitation, difficult personality characteristics and socially obtrusive behaviour), two involved family circumstances (finances, limits on family opportunities) and the remaining three profiles related to significant respondent issues (excess time demands, sensitivity to the reactions of others and a lack of access/availability to social support systems).

At programme-end, three of these stressors were no longer considered significant including one family issue (limits on family opportunities) and two respondent issues (excess time demands and sensitivity to the attitudes/responses of others). No changes in child issues were noted however it would be feasible that increased adaptive behaviour and decreased target behaviours as noted during the programme, could account for some of the reduction noted in the previous significant scales.

Over the long-term follow-up period, this family also experienced relationship difficulties and Eliam's mother felt increasingly frustrated about her personal occupational options/role within the family context. Eliam experienced ongoing schooling and health issues which had an ongoing negative and pervasive effect on the family and in particular, on his mother as the primary caregiver as she was also endeavouring to conclude her own studies/future opportunities. As a result of these factors, long-term follow-up results showed 12 elevated stress profiles. The two

family issues evident at baseline were also evident at follow-up. One extra child issue became significant (concerns over future employment/educational opportunities) and three extra respondent issues became significant (poor health/mood, over-protection/dependence and over-commitment/ martyrdom).

Amy (N09). At baseline, Amy's mother recorded six elevated stress profiles. No family issues were noted indicating a well-functioning family unit without financial or opportunity constraints. Amy's mother had a recognised and chronic medical condition which required ongoing medication and influenced her ability to perform parenting duties at times. It is believed that this medical issue contributed to the elevated poor health/mood profile noted, as opposed to role dissatisfaction or depressed affect per se. Other elevated respondent profiles included sensitivity to the reactions/attitudes of others, over-commitment/martyrdom and a lack of access/availability to social support networks. Stressors associated with child issues included future concerns around education/ employment opportunities and difficult personality characteristics.

At programme-end, significant child issues increased and changed. Physical incapacitation and socially obtrusive behaviour became significant whereas future concerns were no longer considered problematic. At this stage, Amy was preparing to enter school from a previous limited involvement in the pre-school environment. Amy's mother had serious concerns about Amy's ability to function at school following a failure to obtain educational resource funding. Respondent concerns reduced with a lack of access/availability to support systems and over-commitment/martyrdom no longer presenting as significant issues. The latter scale re-gained importance at long-term follow-up (possibly due to increased concerns around Amy's entry to school). One other respondent issue was elevated at this time (sensitivity to the attitudes of others) and the other significant profiles at follow-up were child issues (difficult personality characteristics and socially obtrusive behaviour) indicating concerns surrounding current difficulties with the condition of ASD only.

Elliot (N10). At baseline, Elliot's mother recorded the highest number of significant stressor scales (13/15) compared with other participants and these concerns remained significant during the programme and follow-up periods with only one fluctuation noted in the financial area at the post-programme stage. Concerns included respondent issues (poor health/mood, excess time demands, sensitivity to the attitudes/responses of others, over-dependence/protection, lack of social support), family issues (lack of family integration, limits on family opportunities, finances) and child issues (difficult personality characteristics, socially obtrusive behaviour, physical incapacitation, lack of activities and future concerns over educational/occupational opportunities).

Two major influences were proposed to contribute to these outcomes: child variables and family issues. Elliot was the middle child in a family of three children. He was functioning at the lower end of the autistic spectrum. He was non-verbal, was unable to fulfil self-care tasks and required 24 hour supervision. In addition to the demands of caring for Elliot and his siblings, the relationship between the parents was difficult and eventually led to a complete family breakdown. In spite of these stressful life situations, Elliot's mother did not become pessimistic or assume that she was the only person able to assist Elliot to function satisfactorily.

Little change in these stressors was noted during the programme and follow-up period despite mum's report that Elliot's behaviours had improved and she had successfully generalised behaviour techniques to her other two children.

Summary of Group Two Results

As has already been noted, Group Two participants had significantly more elevated stress profiles at baseline and during the programme and follow-up period compared with Group One participants. Four out of five of Group Two participants experienced relationship difficulties during the study period and three of these went through separations during or subsequent to the end of the programme/follow-up period (one later reconciled). It is believed that these relationship difficulties contributed

substantially to elevated stress levels particularly in terms of reduced social support, poor mood and limits on family opportunities.

At baseline all parent participants had significant concerns about features associated with their child's ASD. Difficult personality characteristics were problematic in all cases and socially obtrusive behaviour affected four of the five participants. In addition, four of the five participants reported significant concerns about the future occupational and educational opportunities for their child and three were concerned about the lack of activities available to their child.

With respect to respondent concerns, all participants were significantly concerned about a lack of access or availability of social support services/networks and all reported significant concerns about a sensitivity to the attitudes/responses of others. High levels of overdependence/protection (4/5) and over-commitment/martyrdom (3/5) are believed to stem from a desire to help and protect the child. Poor health/mood affected four of the five participants at baseline and excess time demands were noted to be significant for three participants.

Perhaps the biggest difference between Group One and Two results was the increased number of stressful family issues in Group Two. Four out of five Group Two participants felt that family opportunities were constrained or limited and financial constraints were notable for three Group Two participants. While a lack of family integration did not appear notable for the majority of Group Two participants at baseline (1/5), decreased family opportunities were more likely to be a result of parent/parent relationship difficulties than parent/child difficulties.

All Group Two participants reported fewer stressors at *programme-end.* No single stressor category appeared to be significantly reduced compared with other categories but reductions were noted in respondent issues (excess time demands, sensitivity to the attitudes of others, lack of access/availability to social support networks, over-commitment/ martyrdom), child issues (lack of activities, concerns about future opportunities) and family issues (finances, limits of family opportunities). Corresponding rises were also noted in child issues (physical incapacitation, socially

obtrusive behaviour) and family issues (lack of family integration). These results indicate that the programme may have had more effect on respondent issues when participants were facing family difficulties or were affected by poor mood issues. In contrast, in Group One where no family or mood issues were prevalent at baseline, the programme appeared to be of benefit in alleviating child issues. Respondent issues were not affected in the former group possibly because they were not compromised to begin with. Note that in this study, respondent issues (e.g., poor mood) and family issues (e.g., lack of family integration/opportunities) were significantly correlated while child issues (e.g., difficult personality characteristics and socially obtrusive behaviour) occurred regardless of other issues. Thus, for all participants, the stressors surrounding the condition of ASD (and pertaining to the child) were notable prior to the programme regardless of other family circumstances.

This finding is consistent with a number of other research articles which have found that the condition of ASD is a significant stressor for family members (e.g., Hastings & Johnson, 2001; Koegel et al., 1992). In addition, where mood and family difficulties are also significant stressors, supportive education (such as this programme) appears to be of benefit primarily to the respondent. Where no such extra stressors are obvious, the benefit of the programme appears to be in favour of child issues.

Given that the group without extra stressors (Group One) failed to experience significant changes in respondent issues, it is felt that the programme would benefit from being placed second to or alongside alternate measures designed to alleviate mood or family disturbance where these features are noted at baseline. Furthermore, the long-term results of individuals with multiple significant stressors (Group Two) indicate that gains due to the programme may be reversed over time if these other features are not addressed. The only participant in Group Two that showed sustained improvement over time was Amy's mother who also reported no significant family problems.

These results re-iterate the importance of focusing on the parent/primary caregiver. Many studies focus on child issues (e.g., behaviour) and so did this research. It should

be noted that behavioural gains both in terms of reduction of target behaviour and increases in adaptive behaviours were achieved but perhaps the results could have been more 'profound' if part of the initial programme contained material addressing self or relationship issues where indicated. Differential studies would be beneficial to determine the effectiveness of such an approach. The utility of the current research design is not without value. Regardless of parent and family stressors, participants were able to effect positive and significant child-behaviour change. Parents are also often more inclined to approach programmes designed at meeting the needs of their child as opposed to themselves or their relationship. Care and sensitivity is required in order to avoid alienating caregivers and reinforcing beliefs about parent 'fault'.

The Stress Profile of New Zealand Parents Raising Children With ASD

In this study, baseline data show that child and respondent issues presented significant stressors for parents of children with ASD. Child issues included difficult personality characteristics, socially obtrusive behaviour and future occupational/educational limitations and concerns. Respondent stressors included sensitivity to the attitudes/reactions of others and a lack of access/availability of social support networks. To a lesser extent respondents also reported significant limitations on family and personal opportunities.

Table 18 shows comparative results from other research into stress associated with ASD. It is proposed that the differences between the two groups in this study in terms of extra familial/health stress may account for some discrepancies with the findings of other researchers. For instance, Group One participants who did not show family or mood difficulties were largely affected by child characteristics associated with ASD (difficult personality characteristics and socially obtrusive behaviour) and one respondent issue (sensitivity to the negative attitudes of others) - an outcome that supports the findings of Holroyd and McArthur (1976).

Table 18

Comparative Results between the Current Research Study and Previous Research Results Concerning Stress Profiles among Families Raising Individuals with an ASD.

	This study	Kodaki / Inanami 1978	Holroyd et al., 1975	Wilton 1986*	Holroyd / McArthur 1976	Bristol 1979
Poor/health/mood		X				X
Excess time demand		X				X
Negative attitudes	**X**	X		X	X	X
Over- protection & dependency		X		X	X	X
Lack of social support	**X**		X	X		
Over-commitment & martyrdom						X
Pessimism			X	X		
Lack of family integration			X		X	X
Limit of family opportunity	**X**		X			X
Finances			X			X
Physical incapacitation				X	X	X
Lack of activities		X		X	X	X
Future occupational/ educational opp.	**X**			X	X	
Socially obtrusive behaviour	**X**					
Difficult personal characteristics	**X**	X	X		X	X

Note. * denotes sample not exclusively containing individuals with ASD.

In contrast, Group Two participants who were undergoing mood or family difficulties indicated stressors in all categories; child (difficult personality characteristics, socially obtrusive behaviour, lack of activities and future occupational and educational concerns), respondent (poor health/mood, excess time demands, sensitivity to the attitudes of others, lack of access/availability to social support systems, over-commitment/martyrdom) and family (limited family/personal opportunities, finances). These results are similar to those reported by other researchers (e.g., Holroyd et al., 1975; Kodaki & Inanami, 1978) who found that family stressors were most predictive of the amount of stress reported by families with children with ASD.

In other cases, direct comparisons between these results and others cannot be made due to process issues. For example, a New Zealand norm sample found significantly elevated profiles in a number of stressors but used a norm sample comprised of developmental disabilities including (but not exclusively) early infantile autism (Wilton, 1986 as cited in Holroyd, 1987). This study also utilised a modified form of the QRS. Given the strength of the QRS for identifying intervention/treatment issues, a large-scale administration of the QRS or similar-type instrument would be useful for determining a New Zealand family response to ASD and stress and also to elucidate cultural differences between New Zealand Māori and European stress responses.

When comparing populations with ASD and 'mental retardation' (Kodaki & Inanami 1978) and populations with ASD and Down's Syndrome (Holroyd & McArthur, 1976), mothers of children with ASD have been found to score higher than the relative comparison group, particularly on child issues (lack of activities and difficult personality characteristics) and respondent issues (poor health/mood, excess time demands, sensitivity to the attitudes of others, over-dependency/ protection).

In this study, child issues produced significant stress profiles in areas concerning future educational/occupational opportunities, difficult personality characteristics and socially obtrusive behaviour at baseline for both groups. Future concerns and a lack of activities were more significant for Group Two participants as opposed to Group One members. All participants had significant concerns with difficult personality

characteristics and socially obtrusive behaviour. The experimental group as a whole also had elevated respondent-stress issues; sensitivity to the attitudes of others and a lack of access/availability to social support networks. Again, Group Two showed increased scores over time with significant outcomes for both of these scales and another three (poor health/mood, excess time demands and over-commitment/martyrdom). Only one family domain scale (limits on family opportunities) affected the majority of the experimental group, yet again, Group Two participants accounted for the vast majority of affected individuals. Thus, it is proposed that the results from the research noted above could be differentiated by consideration of underlying mood or family difficulties.

One finding that was most obvious as being absent as a source of stress for the experimental group is 'pessimism'. This stressor was notable in its low or nil incidence/occurrence at baseline and throughout the programme. Other findings suggest that pessimism is a feature of stress faced by families with children including (but not exclusive to) children with ASD. For example, Holroyd et al., (1975) found that an elevated pessimism profile could identify those parents experiencing *most* stress associated with ASD. This outcome was not evident in this study although a small sample size makes this difficult to determine. In the earlier New Zealand norm group study (Wilton, 1986 as cited in Holroyd, 1987; Wilton & Renaut, 1978), pessimism was also found to be significantly elevated in a population containing children with early infantile autism. However, the mixed nature of diagnoses among participants in this study may mask the relationship between families with children with ASD and those with other disabilities/conditions. Whether the results produced in this current study merely reflect the size and nature of the sample group (parents who chose to actively pursue involvement in their child's behaviour and management) or whether the results do reflect a low incidence of pessimism among New Zealand parents with children with an ASD remains to be seen.

In a more recent study, Koegel et al., (1992) produced a characteristic and durable stress profile associated with children with an ASD. Although this group of researchers used the QRS-shortform and the categories are therefore not directly

comparable with the results of this study, they did find significant stressors largely associated with child characteristics (e.g., level of cognitive functioning, child's ability to function independently, acceptance into the community). To a lesser extent they also found respondent issues (e.g., life-span care) and family issues (e.g., limits on family opportunities) to have significance for this group of families. The child issues noted are largely contained within the following scales: difficult personality characteristics, social obtrusiveness and future concerns over occupational/educational limitations as per the findings in the current study. Respondent issues noted by Koegel et al., (1992) are contained within a number of the profiles used in the full QRS (e.g., excess time demands, sensitivity to the attitudes of others and to some extent, lack of social support and over-commitment/martyrdom). The sensitivity to others and lack of social support issues were significant factors in the current experimental group with the other noted profiles becoming significant for those respondents who were undergoing mood/family difficulties. The family issue noted in Koegel's study was also a significant factor for the current study group. Thus, the results found in the current study support the stress profile developed by Koegel et al., (1992) although further distinctions on the basis of those participants suffering mood or family problems may yield some important differences in a 'characteristic' stress profile for parents/families of children with an ASD.

CHAPTER 8

Parent Voices

At the conclusion of the programme, parent-participants were invited to evaluate their experiences and comment on various features of the programme. Parent-participants will be referred to as 'parents' throughout this chapter. The evaluation was divided into three parts; a) comparison and comment on the two treatment components (applied behaviour analysis of behaviour and social understanding), b) consideration of the contribution of attributions to programme outcomes and c) evaluation of programme features including group format, length and intensity of the programme and other issues. Each question was rated using a five-point Likert scale. Where parents chose to comment, their comments have been repeated verbatim. References to specific children have been removed to protect the child's identity. A teacher who was supporting one of the parents was also invited to evaluate the programme. Her comments were noted but ratings were not included in the following analysis.

Part 1: Evaluation of Course Components – ABA versus ToM.

In the first part of the evaluation, parents were asked to rate the two phases (applied behaviour analysis and social understanding) of the programme separately. Each section contained questions relating to usefulness of material, clarity of presented information, participant confidence in the use of techniques introduced both before and after the programme and potential future use of course components. Parents were reminded of each course component prior to answering the evaluation questionnaire and written comments were invited throughout the evaluation. At the conclusion of this analysis, parents were asked to rate their preference for one component or the other and the results are discussed.

Applied behaviour Analysis of Behaviour

Usefulness of material. Rating scale scores ranged from 1 (not useful at all) to 5 (extremely useful). All parents rated the applied behaviour analysis section as useful (range 3-5) with an average score of 4.4 over all participants (n=10). There were no differences noted between the two Groups even though Group One participants had received this part of the programme first.

> I learned to focus on [my child's] needs rather than the behaviour after (Group 2 participant).
>
> I knew most of it but the application to practical situations and review of it was brilliant (comment from supporting teacher).

Clarity of information presented. Most parents found the information was presented in a clear manner (range 2-5) although it is notable that the one parent who did not speak English as a first language found the information less clear (score = 2). An average rate of 4.1 was found (1 – unclear/confusing to 5 – very clear/easy to understand). There were no differences found between the two groups.

One parent noted that although the information was clear, it took a number of tries to understand the informational concepts presented, while others noted the usefulness of prepared notes for ongoing reference.

> I still find it a little confusing but the handout notes are great to re-affirm/re-assure the correct track to take (Group Two participant).
>
> One of the most useful and comprehensive sets I've seen outside a text book! (comment from supporting teacher).

Confidence in use of technique. Confidence in using the applied behaviour analysis techniques *prior* to the commencement of this programme varied greatly. One parent noted she had been using some of the applied behaviour analysis techniques previously while others commented that they had no previous experience or information about this approach. Overall the experimental group rated themselves

as less than 50% confident with the techniques and concepts used in this section prior to the programme (group average = 2.8, range 1-5 where 1 = not confident and 5 = very confident). There were no differences between the two groups.

Confidence in using this technique *after* the programme had risen to an average rating of 4.1 (range 3-5). One parent noted that she had to continue to practice the techniques now in order to maintain confidence. No group differences were found.

Potential future use of techniques learned. The experimental group indicated they would be likely to use the approach again in the future (average 4.4, range 3-5 where 1 = not likely to use applied behaviour analysis techniques again and 5 = highly likely to use applied behaviour analysis techniques again). Two parents noted hesitations about the use of the applied behaviour analysis approach in the future but still felt they *may* use the techniques. Interestingly, one of these two parents was the same parent who noted previous familiarity with the techniques prior to the course. Their hesitation stemmed from their observation that such techniques were 'hit and miss' with their child. Another parent noted that while they were familiar with the approach they had not often implemented it as they felt it required them to be 'one step ahead (of their child) at all times'. This concern was noted by more than one parent participant as being a potential stumbling block for implementing the applied behaviour analysis techniques especially when the parent was tired or stressed.

> When things are going well this approach is great – when you're tired it's a lot harder to stay ahead (Group Two participant).
>
> Have to be quick and on the scene to sort out (Group Two participant).
>
> I think this approach requires much more 'one to one' in terms of implementing strategies. Parents also need much greater support to implement this approach (Group Two participant).

Note that all these comments came from Group Two participants who had already received the social understanding material. It could be feasible that exposure to the social understanding approach prior to the applied behaviour analysis material had

made this group wary of the extra demands required by the applied behaviour analysis approach. However, the general comments that follow show that participants in both groups appreciated the utility of the applied behaviour analysis approach.

General comments.

> This section helped me to look beyond what [my child] was doing to *why* s/he was doing it, making it easier to understand/cope with (Group One participant).
>
> I feel this is an awesome approach that I can relate back to when not "in crisis". Makes me feel closer and more understanding of [my child's] situation. Can't say I've used it "in crisis" as yet – not appropriate (Group Two participant).
>
> I have a better understanding of why [my child] might behave inappropriately at times (Group Two participant).
>
> I feel that the F/A approach empowers the parent and allows us to step back and take time to look into and understand the ASD world (Group Two participant).
>
> Can be used with all children (Group Two participant).
>
> I'll use this on many children (comment from supporting teacher).

Summary of Parent's Views of Applied Behaviour Analysis Section of the Programme

Overall, parents found the applied behaviour analysis material to be useful and clearly presented. Parents found that their level of confidence about the applied behaviour analysis approach increased over the course of the programme and most reported they were likely to utilise the techniques again in future situations involving their child's (and other children's) behaviour/s. Parents noted increased understanding of their child's behaviour/s and the ability to utilise the learned techniques with the behaviour of other children. However, concerns were noted about the utility of techniques when parents were tired, the requirement for immediacy of response/high parent input and the need for support to implement techniques.

Social Understanding/ToM

Usefulness of material. All parents rated the social understanding section as useful (range 3-5 where 1 = not useful at all to 5 = extremely useful) with an average score of 4.5 over all participants (n=10). There were no differences noted between the parents in Groups One and Two.

> Made me aware of things that I had not even thought about in regards to social behaviour and [my child's] lack of understanding (Group Two participant).
>
> It was like a key to open a locked door (comment from supporting teacher).

Clarity of information presented. Most parents found the information was presented in a clear manner (range 3-5 where1 = unclear/confusing and 5 = very clear/easy to understand) with an average rating of 4.3 over all ten participants. Again, no between-group differences were found.

As with the applied behaviour analysis section, one parent noted that repetition of the presented concepts was necessary to enhance clarity of the information.

Confidence in use of technique. Confidence in this technique *prior* to the commencement of this programme was very low. One parent noted they had been using some of the techniques inherent within this approach (e.g., pictures/charts), "knowing they worked but not understanding why". All other parents reported they had no previous experience or information about this approach, but more than this – some noted doubts or outright cynicism of the concept of social understanding as a technique to alter behaviour prior to the programme.

> Thought it was a load of rubbish (Group Two participant).
>
> I'd never heard of it and was initially fairly sceptical (comment from supporting teacher).

Overall the experimental group rated themselves as less than 50% confident with the techniques and concepts used in this section prior to the programme (group average = 1.8, range 1-3, where 1 = not confident and 5 = very confident). There were no differences between the two groups.

Confidence *after* the programme had risen to an average rating of 4.3 (range 3-5) with no differences between the two groups. As with the applied behaviour analysis approach, one parent noted that they had to continue to practice the techniques now in order to maintain confidence. Others were surprised by the results they achieved.

> Seen the results, quite impressed, works well in crisis and can be backed up afterwards (Group Two participant).
>
> I am quite astounded at the effectiveness of this approach (Group Two participant).
>
> It really works! (comment from supporting teacher).

Potential future use of techniques learned. The experimental group indicated they would be very likely to use the approach again in the future (average 4.7, range 4-5 where 1= not likely to use techniques again and 5= highly likely to use the techniques again). There were no hesitations noted about the use of the social understanding approach.

> Use it every day (Group Two participant).

General Comments:

> I found this approach had a more marked positive effect on the particular behaviours we were trying to change (Group One participant).
>
> Surprising results able to be used effectively with non-verbal child... (Group Two participant).
>
> Use least verbal at stressed times. More visual useful. (Group Two participant).

> I will definitely continue to work with this approach (Group Two participant).
>
> Once I understood how to apply and [my child] accepted the information it was a treat to see him/her realise that I understood him/her without the screaming (Group Two participant).
>
> Would be helpful as a guide for teachers/educators to explain the lack of understanding that ASD children have [i.e., the lack of understanding of others about ASD – author comment]. Would hopefully open their eyes and allow some consideration towards the individual child's needs (Group Two participant).
>
> I think the ASD part is excellent and *simple* (and effective) and therefore parents are more able to implement it independently. The applied behaviour analysis requires a much greater level of understanding, and much more time should be spent on developing and supporting strategies to put into place (Group Two participant).
>
> I find it hard to believe that something so simple can achieve so much and is relatively unknown (comment from supporting teacher).

Summary of Parent's Views of the Social Understanding Section of the Programme

Overall, parents found the social understanding material to be useful and clearly presented. No parents had prior knowledge of the concepts presented in this section. Parents found that their level of confidence about the social understanding approach was initially very low but increased over the course of the programme and most were highly likely to utilise the techniques again in future situations involving their child's behaviour/s.

The dominant positive feature of the social understanding component as noted by parents was the simplicity of the concepts and the effectiveness of applied techniques in altering behaviour. Other positive features noted included the ability to utilise techniques in times of 'crisis' or parent stress, the improvement in understanding child behaviour and increases in quality of relationship with the child. No concerns were noted.

Participant Preference for Applied Behaviour Analysis Versus Social Understanding (ToM)

Parents were asked to rate which approach (applied behaviour analysis versus social understanding) they found more useful. There was a clear preference for the social understanding approach over the applied behaviour analysis approach alone but a combined approach was also popular. In terms of individual responses, 40% of parents clearly preferred the social understanding approach while 20% preferred the applied behaviour analysis approach. The remaining 40% chose a combination of both approaches as being most useful in their particular situation.

An analysis of the preferences of parents in Groups One and Two yielded some interesting results. Of those who received the applied behaviour analysis information first, one clearly preferred the applied behaviour analysis approach, three clearly preferred the social understanding approach and the remaining parent preferred a combination approach. Thus, where applied behaviour analysis was presented first, the majority of parents actually preferred the social understanding approach. In contrast, in Group Two where the social understanding approach was presented first, one parent clearly preferred this option, one again chose the applied behaviour analysis approach as their intervention of preference while the remaining three group members preferred a combination approach. Thus where social understanding material was presented first, the majority of parents preferred a combination approach. It has already been ascertained that the majority of Group Two members were facing considerable personal and family stressors. An analysis of the effects of these stressors on component preference could yield some useful descriptive information and would benefit from further investigation.

These results suggest little evidence of an order of presentation effect and indicate that parents were not necessarily 'sold' on the first approach they practised. Those who saw merits in using both approaches tended to see benefits in using each at different times or for different purposes;

> I find I use each approach in different situations i.e., applied behaviour analysis – forward planning. ASD – crisis (Group Two participant).

> I think that a combination of the two has been more successful with [my child] – being able to analyse his/her behaviour using an applied behaviour analysis approach but also to explain things to him/her about 'social rules' (Group Two participant).

> Both useful separately but put the two together and you have gold (Group Two participant).

It appears that the different components may be meeting different needs for both the target child behaviours and for the parents. Two of the respondents who chose the combination approach had children with limited verbal abilities and particularly challenging behaviours. Both noted the utility of clearly defined applied behaviour analysis approaches in determining the communicative function of the target behaviour and then replacing the non-functional behaviour with a specific and functionally-equivalent new behaviour. Both parents also reported that the social understanding enhanced their own understanding and used this approach as a conceptual framework within which to assess their child's behaviour/s, shape expectations and guide the child in future behavioural learning.

The suggestion that positive results gained in a particular phase of the programme could favourably predispose participants to that particular approach would seem logical. However, no such relationship was found in this study. In one case where all three target behaviours reached ceiling or floor levels during the applied behaviour analysis phase, the parent did report a preference for this approach. However, in a second case where two of the three target behaviours reached ceiling levels during the applied behaviour analysis phase, the second parent reported a preference for the *social understanding* approach. Moreover, in a third case, a parent who recorded a preference for the *applied behaviour analysis approach* actually recorded floor/ceiling levels of behaviour *during the social understanding* phase. As the evaluation period took place after parents had received both course components, it is possible that they may be viewing the effects of the programme in terms of combined techniques rather than either component alone.

Personal parenting style and beliefs might also be expected to determine preferences in approach chosen. This could be a useful goal in future research to determine which parents may benefit from each approach in those cases where one approach is clearly preferred over the other. Certainly there were no strong enduring relationships noted between outcomes for child behaviour and parents' preferred approach.

Overall, these results demonstrate the benefits of offering a combined approach. However, data also suggest that the social understanding approach may be preferable to the applied behaviour analysis approach if either were to be offered alone.

In terms of order of presentation, no clear preference emerged, although there were benefits noted by parents when utilising the social understanding approach first. The social understanding approach was perceived by participants to be simpler and user-friendly. It has been proposed earlier that the applied behaviour analysis approach may be considered too 'technical' and cumbersome and thus may deter parents from utilising techniques or lead to decreased parental efficacy. Participants could be expected to have experienced successful behavioural change when implementing social understanding techniques and their efforts would be reinforced through observing positive behaviour change. The more 'complex' approach (applied behaviour analysis) could be built upon these initial successes for persistent behaviours or once participants were comfortable with viewing behaviour in a more structured manner. There is considerable support for this proposed order of presentation as the social understanding approach clearly changes behaviour. Those behaviours resistant to this initial approach could then be considered in the light of the equally robust applied behaviour analysis information and techniques. Participants would be gradually up-skilled in the level of behavioural intervention and information they acquire and ethically, both approaches have significant positive effect on target behaviour.

Part 2: Behaviour Change

As shown in Chapter One, the majority of target child behaviours changed in a positive direction. In this part of the evaluation, participants were asked to rate their perceptions of these behaviour changes. This evaluation was necessary to clarify issues of social validity (i.e., did the behaviour change mean something to the participants - Hawkins, 1991; Wolf, 1978) and also to determine parent beliefs regarding behaviour changes noted. Of particular interest was whether the parent could accurately gauge the presence and movement of behaviour change and also whether the parents attributed changes noted to the programme or whether they believed other factors were significant.

Detection of Behaviour Change

Parents were asked to rate their perception of behaviour change noted in the three target areas over the programme. Each behaviour was rated on a five-point Likert scale where 1 = negative behaviour change, 3 = no change and 5 = positive behaviour change.

Group averages showed that parents felt that behaviour had changed in a positive direction for each of the three behaviours in the social, communication and preservative domains. There were no significant differences noted between the parents in Groups One and Two.

All parents rated high levels of positive behaviour change in all three areas of the 'autistic triad'; social, communication and perseveration. The majority of parent's ratings were consistent with actual behaviour change recorded in Chapter Three. The two exceptions to this observation both occurred in the perseverative behaviour domain and are discussed below.

One parent (N10) felt there was no change in behaviour 3 – smearing food. Examination of behavioural records showed partial support for this view. The

behaviour showed no change in trend during the programme but the rate of behaviour both during the programme and at follow-up were at lower levels than the rate of behaviour recorded at baseline. In other words, the child was still engaging in the problem behaviour at the conclusion of the programme but at a lower rate than that recorded during baseline. To the parent, this behaviour was still problematic and her perception that the behaviour showed no change was possibly based on the simple fact that it was still present. In other words, the behaviour change was not socially valid for this parent even though positive change was recorded.

In contrast, another parent (D05) noted positive behaviour change where *no change* was evident in the behaviour recordings taken earlier. Further examination and parent report found that the behaviour in question had improved qualitatively under conditions where the behaviour was deliberately provoked. Initial low levels of baseline behaviour reflected a tendency of family members to avoid situations which provoked target behaviour. In effect therefore, the data collected did not reflect the quality or extent of behaviour change which the parent reported was marked and positive because the changed context within which the behaviour occurred was a confounding factor. At programme end, family members were no longer avoiding situations where this behaviour was likely to occur – a positive outcome. When the issue of context was elucidated, the behaviour change was reported as socially valid for the parent.

Attributions of Behaviour Change

Parents were asked to rate the amount of behaviour change they attributed to the programme as opposed to other factors. On a scale of 1 -5 (where 1 = 0% of behaviour change was attributed to the programme and 5 = 100% of behaviour change was attributed to the programme), the experimental group average rating was 4.0 (range 3-5) indicating all parents attributed *at least* 50% of the observed behaviour changes to the programme and the group average was equivalent to 75% of behaviour change being attributed to the programme.

Parents were then asked to note other relevant contributing factors. Those parents who attributed *all* behaviour changes to the programme reported increases in their own understanding, increased confidence and knowledge as adjunct changes that supported the programme effect. Those who attributed less than 100% of the changes noted to the programme reported increased consistency in their approach to behaviour, increased monitoring, listening/understanding and acting on increased knowledge/ understanding as being important factors effecting positive behaviour change.

It is interesting to note that both sets of parents (those who attributed all positive behaviour change to the programme and those who did not) noted similar reasons or contributing factors for the changes observed. In effect they were (without exception) describing changes in their *own* behaviour as being significant factors in the outcomes noted for their child's behaviour change/s. During the programme, parents were required to monitor their child's behaviour (both in terms of identification of target behaviours and record-keeping). Both parts of the course imparted new knowledge and encouraged active and practical application of this knowledge to child behaviour. Moreover, parents met together weekly to discuss outcomes, design new interventions and problem-solve behavioural issues both for other participants and themselves. The changes noted (e.g., increased monitoring/ understanding/ confidence) were parent behaviour changes. The implicit parent behaviour changes described here were identified by some as being implicit within the programme and therefore they attributed all (100%) child behaviour change to the programme. Others identified these parent behaviours as distinct from the programme and did not attribute these parent factors to the programme in turn.

Part 3: Other Programme Features

Group Format

This study was presented in a group format and parents were invited to comment on their experiences and thoughts of being involved in a group process.

All parents felt the group experience had been positive. There were no differences between the two groups. Obviously parents who chose to participate were aware of the group format design, so the sample could be considered to be biased as those not wishing to participate in a group would not be expected to volunteer for inclusion in the project. Having said that, the group requirement was not made evident to the researcher as a reason for not applying for participation at any stage and all parents successfully completed the course. There were some initial concerns however, that were uncovered in some comments from parents;

> It didn't turn into a big moan session. I think we all wanted to do something about our kids and were motivated. What a neat group of people (Group One participant).

One parent had some concerns listening to negative comments regarding the school system:-

> On the whole [the group experience] was positive and I felt great when we shared our successes. Great to hear and share but I did find it difficult hearing negatives about school as we are approaching the school system (Group Two participant). ['negatives' referred to here are those spoken about by another group member in discussions – author comment].

Social Networking & Support

Feedback concerning the group experience was positive. Most comments referred to social networking and support. A major feature was the opportunity to build social networks and gain social support. Many of the parents continued to meet together at the conclusion of the course and at least 50% also became actively involved in various support roles (e.g., local AANZ committee), initiated support groups, or joined child-related programmes at least in part due to their increased confidence in knowing others from their group.

Perhaps the most significant comments came from the parents being able to change their perception of social isolation by being part of a group facing similar behaviours and issues. Parents reported feeling increasingly more 'relaxed' as they realised their child's behaviours were shared ('normalised') by others.

> It was great to hear other parent's trials and successes. Often saw my child in a different light! (Group One participant).
>
> Great to be part of a group going through the same process and having similar behaviour difficulties (Group Two participant).
>
> Loved talking and listening about our children, loved watching [my child] interact with [another participant's child with ASD] (Group One participant).

Another benefit of the group format was increased learning due to hearing and sharing the experiences of others within the group.

> Group situation was a major bonus as we only chose 3 behaviours (plenty thank you) we were then able to learn off other peoples examples (Group Two participant).
>
> Good to share experiences, pick other's brains, get helpful suggestions (Group One participant).
>
> Learn case by case, all unique (Group Two participant).

One of the goals of this research was to develop a socially valid, short-term intensive group programme and ascertain the effects of the group process as reported by both behaviour change and participant-report. Behaviour change results shown in previous chapters (Chapters One and Two) have shown that significant changes can be made within a group process. Parent reports indicate that socially valid changes can be achieved within a group programme. Moreover, besides successful presentation and implementation of course material, the group format was identified as providing participant support, increasing participant social networks, decreasing feelings of social isolation/alienation, contributing positively to 'normalising' child behaviour and maximising learning through sharing experience and course-related outcomes. A

further advantage of the group format was that training could be carried out in a relatively short period without excessive reliance of professional direction and support.

Length/Intensity of Programme

This programme ran for a total of nine weeks and three behaviours in three domains were targeted for practical intervention using two different approaches. Parents were asked to comment on the length/intensity of the programme. Nine parents chose to comment on this part of the evaluation and 67% felt the course length was comfortable or ideal.

> Perfect! (Group Two participant).
>
> A lot to take in but a good length. Any shorter and I think I would not have coped (Group Two participant).
>
> The length seemed to be just right. Any longer might have seemed a chore (Group One participant).
>
> It was ideal because such progress was being made it was not boring (Comment from supporting teacher)
>
> Good length. Not to long. Not to short (sic) (Group One participant).
>
> Good even though it seems like we rushed through the programme (Group One participant).

Two parents felt they could have had longer to focus on individual behaviour;

> Could get more out of it with more time (Group Two participant).
>
> Making it slightly longer would give more time to focus on one behaviour before starting on the next (Group One participant).

One parent felt that the ToM section could have been shortened due to the simplicity of the technique;

> Less time could be spent on the ToM component because it is relatively simple to do and much more time put into the applied behaviour analysis (Group Two participant).

One final section allowed parents to make any other comments/suggestions about the programme. These comments generally referred to getting the programme into schools (2 comments) and positive comments on the relationship between the researcher and parents (2 comments). A specific suggestion was made about increasing the use of telephone contact for monitoring purposes.

Summary

Overall, parents evaluated the programme very positively. Both components of the course received positive reviews. There was a clear preference for the ASD (social understanding) approach or a combined ASD/applied behaviour analysis approach as opposed to an applied behaviour analysis approach by itself. The ASD component was perceived to be simplistic and effective while the applied behaviour analysis approach was perceived to require greater professional input (i.e., less parental independence) and support to implement. There were no differences between the two experimental groups who received different methods of instruction initially, nor was behaviour change a consistent factor in predicting parent preference of programme components.

Parents were able to rate behaviour change consistent with actual behaviour change observed and verified during earlier objective measurement. At the same time, parents rated 75% of observed change as being attributable to the programme. Other significant factors for attributing change included parental consistency, increased understanding, monitoring and confidence with techniques – all factors which were implicit components of the programme procedures but were not necessarily identified as such.

The group format was valued and the programme length/intensity was generally perceived as comfortable. Issues/suggestions identified by parents included the utility

of this programme in the school setting, increased use of telephone contact for monitoring purposes and positive relationship experiences with the researcher.

In conclusion, the evaluation process yielded some informative insights into the administration of the programme and provided further support and clarification of positive behavioural outcomes from the perspective of the parents. The group format was well received and parents identified definite advantages in the group process. It is recommended that this feature of the programme administration be preserved in future applications.

CHAPTER 9

Summary, Discussion and Conclusions

To refamiliarise the reader, this chapter begins with an outline of the results of the previous six chapters. General results are discussed. The utility of the programme and the effect of programme components are examined with reference to the treatment aims and goals outlined in the introduction. The confounding factor of group differences is discussed. Limitations of aspects of the research design and potential future research changes or directions are proposed. The thesis ends with a conclusion section.

Results Summaries

Challenging Behaviour

During the administration of this programme, positive behaviour change was recorded for 97% of target behaviours and 80% of target challenging behaviours were no longer reported as problematic or evident at the conclusion of the programme by parents. Challenging behaviours were identified within each triad area of ASD for intervention. All socialisation and communication target behaviours and the majority of rigid/restricted target behaviours changed in a positive direction during the programme. Maintenance and improvement of gains continued at seven-month follow-up.

The programme consisted of two components; (1) applied behaviour analysis, and (2) social understanding based on Theory of Mind (ToM). Both course components produced significant change in challenging behaviour within the first four weeks of the programme and neither component was found to be superior to the other. Both techniques produced effective changes across all areas of the triad of impairments. Results showed that the social understanding component (ToM) may have some advantage over the applied behaviour analysis component in being able to produce

larger effects in shorter periods of time. Social understanding material also appeared to have an additive effect and continued to improve outcomes achieved using applied behaviour analysis. The applied behaviour analysis component, in contrast, did not improve social understanding outcomes.

Adaptive Behaviour

Adaptive behaviours were not targeted for intervention during this study. They were measured in order to determine whether the programme had adjunct effects on behaviours other than those under investigation.

Results showed that all children experienced marked increases in their adaptive functioning level over the course of the programme and follow-up period. Two comparative analyses were undertaken. In the first analysis, experimental group outcomes were compared with an ASD-based norm population. At baseline, most of the experimental group were functioning above 75% of the ASD norm population and one child was functioning above 90% of the ASD-norm group, indicating that the experimental group were functioning at a high level overall. At the end of the programme, six children were functioning above 90% of the ASD-norm group and at long-term follow-up, eight children were functioning above 90% of the ASD-norm group. Individuals with low levels of functioning at baseline tended to show most gain *after* the programme. The relationship between rate of adaptive behaviour gain and level of functioning needs to be clarified. Gains were maintained and improved over the follow-up period.

While it is important to assess gains in relation to other peers with ASD, most families value and expect behavioural outcomes to be compared with non-ASD, age-equivalent peers. This second group made up the second comparative analyses. At baseline, the experimental group was functioning at an adaptive behaviour level that placed them within the lowest one percent of the general population. A significant gain was noted in the average level of adaptive behaviour functioning for the whole group during the programme period. However, the average level of adaptive

behaviour functioning for the entire experimental group remained well within the lowest 20% of norm-based peers. Average group gains beyond the programme period were not significant.

Individual analyses showed that ninety percent of participants made observable gains in adaptive functioning scores compared with an age-equivalent, non-ASD population group. Most individuals experienced significant gains in terms of approaching (or exceeding) age-equivalence (non-ASD norm) in all domains during the course of the programme. Adaptive behaviour gains were made primarily within the daily living skills domain, followed by socialisation and communication domains respectively. Results indicate that gains made in daily living skills and socialisation domains occurred at a higher rate in the programme period. Children gained an average of 13.5 months of adaptive behaviour skills over the nine-week course (range 0 to 42 months) and gains continued to be made at rates above baseline even when interactions with the researcher and other group members ceased.

Attributions of behaviour

There was little evidence of significant change in parent's attributions of behaviour throughout the period of study. All parents of children exhibiting challenging behaviours associated with ASD in this study, tended to rate the behaviours as being consistent, unique and outside the control of the child. Parents used both dispositional and situational attributions to explain behaviour and had a slight tendency to favour dispositional factors before training.

Comparison of the contribution of the two course components revealed that the social understanding component produced little enduring change in attributional factors compared with baseline. The exception to this observation was that behaviour was considered to be slightly more unique following social understanding instruction. Presentation of applied behaviour material produced a decrease in the perception of consistency and a slight decrease in parent's perceptions of 'uniqueness' of behaviour. This finding will be discussed in the next section.

Parental Locus of Control

Group participants were considered to have positive parental efficacy prior to commencing the programme. They had a balanced view of responsibility for child behaviour and generally did not believe that their child controlled their lives. Nevertheless, participants also believed they had little control over their child's behaviour at baseline.

Significant changes were noted in perceived parental efficacy and parent-control domains over the course of the programme and follow-up. Group differences were noted. Group One participants experienced significant improvements in parent efficacy at the programme midpoint and these results were maintained to programme end but reverted to baseline levels at follow-up. In contrast, both groups experienced significant improvement in their own belief about control over their child's behaviour and these improvements were maintained over time.

The differential effect of the two course components on these outcomes is unclear. There is a suggestion that improvements followed administration of the applied behaviour analysis component but this proposal requires further investigation. In most comparative analyses, no differences were found between the groups or course components.

Stress/strain

Parents of children with ASD in this study reported a number of significant respondent and child stress profiles. Parents were concerned about the negative attitudes of others towards their child and a lack of actual or perceived social support. Child issues produced significant stress profiles in areas concerning future educational/occupational opportunities, lack of activities available for the child, difficult characteristics associated with the child's condition (ASD) and socially obtrusive behaviour. Only one family domain scale (limits on family opportunities) affected the majority of the experimental group. Stress profiles decreased over the

course of the programme, indicating that the programme itself did not increase stress or introduce any new form of stress to participating families.

The programme appears to have significant effect in mitigating particular child difficulties/stressors – most notably difficult personality characteristics associated with ASD and the socially obtrusive nature of ASD behaviours. Results indicate that the programme may have had more effect on *respondent* (i.e., parent) stress when participants were facing family difficulties or were affected by poor mood issues. Where these difficulties were not evident, the programme appeared to be of more benefit in alleviating *child* issues. It is proposed that family and mood difficulties may account for discrepancies noted between stress outcomes in various previous research examples. Stress reductions were not necessarily maintained when negative family and mood issues were present. However, positive behaviour outcomes appeared to occur regardless of the level of stress experienced by the family. In order to maximise outcomes for families, it is proposed that future administration of the programme could benefit from being implemented alongside measures and interventions designed specifically to identify and alleviate personal and interpersonal stress issues (e.g., Sanders & Morgan, 1997; Sharpley, Bitsika & Efremidis, 1997; Singer, et al., 1989).

Attempts were made to construct a stress profile for New Zealand families with children with ASD. Small sample size and incongruent research design/methodology hindered efforts to compare the outcomes of this study with previous research but one feature that appeared distinct was a low level of pessimism amongst participants in this study. Further large-scale investigation is required to reinforce observations and clarify cultural differences in stress responses.

Parent voices

Parents reported value in both sets of information presented during the course and they rated the material as being clearly presented. Previous confidence in applied behaviour analysis techniques varied greatly between participants but confidence

ratings improved during the course. Most participants indicated they would be likely to use the techniques again in the future. Parents noted increased understanding of their child's behaviour/s and the ability to generalise the learned techniques to the behaviour of other children. However, some concerns were noted about the utility of applied behaviour analysis techniques. These concerns included difficulties administering this part of the programme when parents were tired or stressed, the requirement for immediacy of response/high parent input and the need for support to implement techniques.

No parents had prior knowledge of the concepts presented in the social understanding component. Parents reported that their level of confidence about the social understanding approach was initially very low but increased over the course of the programme and most were highly likely to utilise the techniques again in future situations involving their child's behaviour/s. Parents reported distinct advantages with the social understanding component, including the simplicity of the concepts and effectiveness in altering behaviour. Other positive features reported included the ability to utilise techniques in times of 'crisis' or parent stress, the improvement in understanding child behaviour and increases in quality of relationship with the child. No concerns were noted.

There was a strong preference reported among parent participants in favour of the social understanding approach or a combined social understanding-applied behaviour analysis approach. There was no evidence of a treatment order effect with respect to this reported preference. The results demonstrate the benefits of offering a combined approach. However, data and parental preference support the utility of the social understanding approach as a possible stand-alone method of intervention for the challenging behaviours associated with ASD.

Behaviour changes were confirmed to be socially valid by the parents and were attributed in the main to the programme content. Parents valued the group format and particularly appreciated the social support networks that it provided, the opportunity to 'normalise' child behaviour with other parents and the ability to maximise learning

by considering the behaviour examples that other group members bought to the group.

Participants were comfortable with the length and intensity of the course. Further suggestions identified by parents included the utility of this programme in the school setting, increased use of telephone contact for monitoring purposes and positive relationship experiences with the researcher.

The evaluation process yielded some informative insights into the administration of the programme and provided further support and clarification of positive behavioural outcomes from the perspective of the parents. The group format was well received and parents identified definite advantages in the group process. It is recommended that this feature of the programme administration be preserved in future applications.

Group Differences

During the process of this study, it was discovered that despite random allocation, Group Two members reported significantly more stress and poor health (including depressive symptomatology) at baseline compared with members of Group One. This finding has some implication for interpretation of the results found and also leads to some interesting potential statements about outcomes. At baseline, the two groups were assumed to be equal. In fact, this was not the case and group comparison results should accordingly be interpreted with caution. At the same time, marked target behaviour change was noted for children within both groups. Significant adaptive behaviour gains were also evident and all behaviour gains were maintained over time. These outcomes indicate that the programme devised and implemented in this study has the potential to produce positive behaviour change regardless of the level of stress and poor mood experienced by the parent/caregiver.

It is also possible that *ToM material* had a much stronger effect than is demonstrated in this study. It was found that neither course component produced a significantly greater effect than the other component. However, Group Two participants recorded

significant behavioural gains during the first four weeks of the course (when they received ToM instruction). These same group members were also significantly more stressed. It is possible therefore, that ToM techniques are capable of producing significant behaviour change *despite* the fact that the parents were significantly stressed. If the issue of parental stress were controlled, ToM techniques may show a more powerful effect (compared with applied behaviour analysis techniques). Further rigorous research would be required to confirm this proposition. Due to design limitations (to be discussed later), some caution should be applied to these proposed outcomes and conclusions. However, further research in this area would potentially be of great value.

Discussion of Results with Reference to Research Aims and Goals

The main purpose of this study was to equip parents/caregivers to be able to effectively and independently manage the challenging behaviours associated with ASD in order to decrease strain and enhance family functioning. It also aimed to develop a short-term intensive programme in which parents were provided with information and techniques to improve parent-child relationships and maximise child development. These aims were met through the administration of a nine-week programme comprising of two components; applied behaviour analysis and social understanding. Parents were able to successfully modify the behaviours they had previously identified as being challenging to their child's development and family functioning. Parents were able to effectively plan, administer and evaluate interventions in the three core areas of ASD and successful behavioural outcomes were achieved. Moreover, parent participants showed evidence of generalisation of techniques over different behaviours, individuals and settings, and they reported satisfaction with the techniques utilised and results obtained.

Challenging behaviours in each area of the 'triad of autistic impairment' were positively and significantly modified when either component (applied behaviour analysis or ToM) was applied and there were no significant differences in outcome between either set of techniques. It would appear that social understanding techniques

were at least as effective as applied behaviour techniques in producing positive behaviour change over all key domains of challenging behaviour associated with ASD. There was some indication that social understanding techniques produced larger changes in a shorter period of time compared with applied behaviour analysis techniques. The strength of applied behaviour analysis has already been documented and accordingly it was considered a robust 'yardstick' against which to measure the newly developed social understanding component. The ability of the social understanding component to attain favourable outcomes shows that it has the potential to be developed into an effective method with which to approach the challenging behaviours associated with ASD.

While no significant differences were found between the two course components in terms of magnitude of behavioural effect, there was some anecdotal evidence that the social understanding component may have superior 'power' as it was able to be used to bring about significant behaviour change for the children of a group of parents who were later found to be suffering significantly more stress (and poor mood) than the comparison group. This finding will be discussed further in this section.

It was hypothesised that *enhanced adaptive functioning* would be an indirect effect of intervention. As outlined in the introduction, the core triad of difficulties for individuals with an ASD are communication, socialisation and restricted interest range. The measurement of all three of these domains in terms of adaptive functioning was particularly useful for ascertaining the effect of the programme on a sample of children with ASD. Both sets of techniques were proposed to offer alternative pathways to facilitate child understanding and development. Adaptive behaviour showed significant and large gains over the course of the programme. All individuals showed gains in three adaptive behaviour domains (daily living skills, socialisation and communication) when compared with an autistic norm group. Most child-participants also showed gains in adaptive functioning when compared with same-age, non-ASD norm groups. Successful gains in all areas of adaptive functioning, but particularly in daily living skills and socialisation, indicate that the

programme developed in this study has specific relevance and benefit for this population.

In the introduction, it was hypothesised that parental behaviour and perceptions would change as a result of theoretical and practical training. An analysis of attribution ratings in this study showed variable results compared with previous research findings. For example, Kelley (1967) found observers were more likely to make internal attributions when behaviour was viewed as unique and consistent. Similarly, it has been asserted that parents of children with difficult behaviours tend to attribute negative actions to dispositional and stable traits (e.g., Baden & Howe, 1992; Booth, 1997; Johnston & Freeman, 1997). In this study, and in support of these previous research findings, behaviour was generally rated as unique and consistent and dispositional (internal) attributions were a feature of Group One baseline records. In contrast, dispositional attributions were *not* a dominant feature of Group Two results. Instead, Group Two participants utilised both situational and dispositional attributions for child behaviour.

It is noted that Group Two participants reported more stress and poor mood compared with Group One participants. Poor or negative mood increases the likelihood of situational attributions (Forgas, 1998). It is possible that Group Two attributions were influenced by 'depressive realism' and parent-participants were more likely to use situational attributions to explain child behaviour. A further finding in this study which did not support previous research results was that while uniqueness and consistency of behaviour remained elevated throughout the programme, Group One results showed a tendency to move towards situational explanations over time.

Analyses of attribution ratings throughout the programme revealed a possible differential effect between the two programme components. During the applied behaviour analysis component, participants in both groups reported decreased consistency and uniqueness of behaviour and increased child-control. That is, child behaviours were perceived as being less likely to recur in the future, other children were more likely to engage in the target behaviour and the child was perceived as

being more likely to have controlled their behaviour and be able to change the outcome.

It appears that applied behaviour analysis training may 'normalise' parent's perceptions of child behaviour. This is not particularly surprising given that the applied behaviour analysis approach focuses on parameters of behaviour that are consistent across all individuals. Combined with the observation that Group One participants showed a movement away from dispositional (internal) attributions, it could be argued that applied behaviour analysis training can improve parent perceptions of child behaviour and their ability to modify behavioural outcomes. In support of this observation, parent locus-of-control outcomes revealed that Group One participants recorded significant improvements in parental efficacy following administration of applied behaviour material. It is noted, however, that none of these positive features were maintained over time.

In contrast, social understanding material appeared to contribute to increased parental perceptions of the uniqueness of behaviour which were durable over the programme and long-term follow-up. When combined with dispositional attributions, increased uniqueness may negatively affect parent perceptions of child behaviour and their ability to modify behavioural outcomes. As it eventuated in this study, presentation of social understanding material did not alter the tendency to ascribe situational or dispositional traits, regardless of order of presentation. However, if dispositional attributions were to be elevated prior to receiving social understanding training, increased perceptions of uniqueness of behaviour may present a threat to the parent-child relationship.

Responses to challenging behaviour are mediated by the attribution of control (Dagnan, Trower & Smith, 1998). Applied behaviour analysis training led to increased participant ratings of child-control. Increased child-control is associated with increased negative emotional response and decreased offers of helping behaviour (Hastings, 1989). Social understanding decreased participant ratings of control when presented first (and changes were maintained over time). Behaviour that

is seen to be outside the control of the child is associated with increased helping behaviour and decreased negative emotional responses from observers (i.e., the parent-child relationship is enhanced).

These observations raise some interesting issues about the relative effectiveness of the two course components that would benefit from direct investigation using parent-child interaction methodology and response measures. The ability to make firm conclusions about the observed outcomes in this study are limited. This is in part due to unsubstantiated validity of the measure used and discrepancies between group baseline data. General design limitations also affect the strength of interpretation of outcomes and will be discussed shortly.

It was further proposed that empowering parents/caregivers to effectively manage child behaviour would result in positive and measurable parent outcomes. However, parents of the children with ASD in this study already showed healthy and positive parent efficacy and beliefs at baseline. This is in contrast to other studies although consistent measures across studies were not used. Successful management of difficult behaviours resulted in parents/caregivers in both groups reporting increases in their beliefs about the level of control they had over their child's behaviour and these increases were maintained over time.

It was proposed that family functioning stress could be relieved by supplementing parenting skills with specific information aimed at reducing challenging behaviours associated with ASD. Parents reported numerous significant stressors associated with living with a child with ASD. Reports of family stress and strain generally decreased over the course of the programme although results were not consistently maintained over time. The programme appeared to have positive effects in mitigating child stressors. However, when parents were experiencing stress or poor mood, the programme appeared to have more effect in alleviating respondent stress (although gains were not durable). These outcomes show that the programme has utility for both the parent and the child with ASD depending on the circumstances of the family.

Identification of parent mood/stress may serve as a predictor for some programme outcomes and would benefit from further independent research.

One of the goals of this research study was to develop a socially valid, short-term intensive group programme and ascertain the effects of the group process as reported by both behaviour change measures and participant-report. Significant behaviour changes were made within the group process. Parent reports indicate that this programme can be successfully carried out in a group format and several advantages of the group format were noted. Training was able to be carried out in a relatively short period without excessive reliance of professional direction and support.

Design Issues & Limitations

Three design issues are discussed here; reliance on parent-report data as a sole outcome measure, the use of a cross-over design and non-validation of treatment components.

Parent Report Data

Reliance on a single type of outcome is criticised as a weakness of some parent training programmes (e.g., Wiese, 1992). The reasons for making the research decision to rely solely on parent-report data in the face of such criticisms were complex. It has previously been ascertained that parents can reliably report behaviour data (e.g, Chamberlain & Reid, 1987). Furthermore, the parents in this study were being asked to undertake a large amount of data gathering. They were required to undertake observation, keep records and plan interventions for up to three behaviours at a time. Requesting further observation reliability checks would likely have over-burdened the participants or made them feel that their own data collection methods were untrustworthy. Either perception may have contributed to programme withdrawal or lack of sustainability.

Validation of behaviour changes could have occurred by requesting another significant adult in the home to keep behaviour records. However, not all homes had

another significant adult and in those that did, the other adult undertook fewer caregiving responsibilities. The target behaviours were chosen for intervention because they caused concern to the primary caregiver (and family). Target behaviours may be viewed or valued differently by other significant adults, thereby introducing another form of potential bias and stress. Hence, for practical reasons (e.g., concern for the load imposed on parents), parent-report outcome data was considered appropriate.

However, attempts were made to attenuate the weaknesses apparent in reliance on parent-report outcome data. For example, when using the Vineland Adaptive Behavior Scales (VABS), the interview form was chosen and open-ended questions were posed so participants were not exposed to leading questions or identical formats. Both the VABS and the Questionnaire on Resources and Stress (QRS) are substantial documents making it difficult for participants to recall previous responses. Parents were required to hand in record sheets every week and no feedback or collation of results was attempted until the conclusion of the programme in order to reduce reference to previous records or ratings. Nevertheless, despite these efforts, treatment integrity is required in order to assess the internal validity of the research findings. Demand characteristics and respondent biases remain valid concerns and reliance on parent-report data as the sole outcome measure is a limitation of the research design.

Use of Cross-over Design

The use of a cross-over design whereby each group learnt, planned, administered and evaluated one set of techniques (weeks 1-4) and then undertook the same procedure for a second set of techniques (weeks 5-9), inadvertently placed some limits on conclusions about the outcomes noted in this study. This was due to the fact that both groups reported ceiling/basement levels of behaviours in the first four weeks, which effectively left some participants with no target behaviour to work with during the second part of the programme. There was an attempt made to consider the additive effects of the two course components by evaluating whether the second component resulted in changes in the trend and level of behaviour in addition to those achieved in

the first part of the course. However, most results showed maintenance of previous results and a number of behaviours were no longer considered problematic prior to commencement of the second part of the course. This outcome made some parts of the course redundant for some participants and the value of the second component was not able to be assessed.

A combination of both sets of techniques was useful for those behaviours that were resistant or slow to change and the programme evaluation showed that the majority of participants reported a preference for a combination of both techniques with a slight bias in favour of information based on theory of mind. However, exposing participants to both components meant that once one set of techniques was learnt, developed knowledge and practise confounded the use of a second set of techniques.

Non-validation of Treatment Variables

A separate but related design issue was that practice of both sets of techniques in the home was not validated. It was noted in the behaviour results section that the intention of the research was to determine the *effect* of providing specific information to parents rather than detailing *how* they applied the information. Hence the design employed in this study was not able to determine precisely what the parents did with the information imparted. There remains a challenge for future research to identify these parent behaviours in attempting to replicate the programme and outcomes described in this study.

One of the research aims was to determine the effect of the two course components (applied behaviour analysis and information based on theory of mind) relative to each other. For the above reasons, the use of a cross-over design in this study did not result in assessment or determination of the relative strength of each course component. The reason for using a cross-over design was based on the considerable empirical support for the utility of applied behaviour analysis techniques compared with an unknown and unsubstantiated approach based on Theory of Mind. In this study, an ethical obligation towards providing participants with information that was known to

alleviate challenging behaviour resulted in a decision to offer applied behaviour analysis material to both groups.

Given that both groups were able to produce positive and effective behaviour change in the initial four week period, it is perhaps now relevant to relax the rigid ethical stance that was taken with this research design. It is proposed that further consideration of the relative strengths of each course component could be achieved using direct comparison of the two course components in future research. This proposed design also has the advantage that the programme length would be halved which would potentially add value and enhance the utility of the programme for families of children with ASD.

Conclusion

Using the programme developed and presented in this study, parents reported consistent and significant behavioural improvements, which were maintained over a seven-month follow-up period. It appears that parents were able to learn specific techniques based on applied behaviour analysis and Theory of Mind/social understanding and were able to apply them to their own child to alleviate behaviours identified by the family as being problematic. Adaptive behaviour gains were measured using parent-interview and were found to be both significant and durable compared with ASD and age-equivalent non-ASD group norms. Parents reported that behaviour gains were socially valid. Results of attributional ratings showed variable support for previous research findings. Both course components showed some evidence of potentially enhancing and/or potentially diminishing parent perceptions of child behaviour. For example, in terms of positive outcomes, applied behaviour analysis training appeared to 'normalise' (decrease parent perceptions of consistency and uniqueness) of target behaviour while social understanding information appeared to decrease negative emotional response and elicit helping behaviour from observers. Parent-participants reported positive parental efficacy prior to commencing the programme. Significant and durable improvement in parent beliefs about their control over the child's behaviours were reported. Repeated parent-ratings showed that the

programme appeared to have significant effects in mitigating particular child stressors, most notably, difficult personality characteristics associated with the condition of ASD and the socially obtrusive nature of ASD behaviours. Results indicated that the programme may have a tentative hierarchical effect. Where respondent stressors were evident, the programme appeared to have more effect on respondent stress, which was not durable over time. Where respondent stressors were *not* evident, the programme appeared to alleviate child-based stressors. While positive behaviour change was reported regardless of the presence of family stressors, it has been proposed that future administration of the programme may benefit from a co-joint programme aimed at identifying and alleviating personal and interpersonal stressors.

There was no evidence to support the utility of one set of techniques (either ABA or ToM) over the other. Both reportedly produced significant and durable behaviour change. There were some indications that the utility and application of 'theory of mind' as a parent-training tool would benefit from further investigation. These indicators are:

a) parent-report behaviour records showed that social understanding (ToM) training produced positive child behaviour change,
b) investigations into family stress reduction indicated that the effect of the social understanding (ToM) material may have been attenuated by the presence of personal stressors that were particularly apparent in Group Two, and
c) parent evaluation data showed a preference for using social understanding (ToM) material alone or in conjunction with other training material.

While there is evidence of the utility of the programme developed and trialled in this study, cautions in interpretation of the results remain. These specific cautions pertain to group differences, sole reliance on parent report data and research design limitations (the use of a cross-over design and non-validation of treatment variables).

Finally, the concept of Theory of Mind (ToM) is based on the assertion that ASD conditions arise from deficits in an inherent ability to understand the intentions of oneself and others. This assertion continues to be the subject of debate. There are limited data and application of the principles of ToM in the research literature to date. In fact, the principles of ToM continue to undergo experimentation and validation. This is the first attempt the author is aware of, to apply techniques derived from ToM principles within a parent training programme. At times, certain aspects of a ToM approach were difficult to operationalise and explain to participants as the whole concept and basis of ToM is outside the knowledge base of most individuals, in contrast with concepts of applied behaviour analysis. This study would have benefited from clearer focussed, empirical-based ToM – however, the field is still in its infancy.

This study was based on techniques devised by Hadwin and associates (Hadwin, Baron-Cohen, Howlin & Hill, 1996) and resulting guidelines (Howlin, Baron-Cohen & Hadwin, 1999) that have already been published with the aim of influencing and supporting practitioner practice. Notwithstanding the research limitations mentioned, the utilisation and application of information based on Theory of Mind shows promise. It is hoped that the results outlined in this thesis will go some way towards encouraging further investigation and empirical validation of ToM principles with the aim of continuing to produce clear and positive assistance for families and individuals with ASD.

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Appendices

Appendix A

Invitation to Participate in Research Programme

Does your child/a child in your care have an Autistic Spectrum Disorder (including Asperger's Syndrome)?

Are they aged between 2 – 10 years?

Would you like to learn new skills to help your child maximise their development potential?

Would you like to learn practical strategies to assist with your child's behaviour?

Do you desire to increase your understanding of your child's condition and/or extend your relationship with your child?

Parents/caregivers are invited to participate in a doctoral level research programme. Participants can expect to receive training in functional analysis techniques and practical instruction in areas specific to Autism Spectrum Disorders. They will identify specific areas of behavioural concern which will become the focus for practical instruction and task development. Participants will take an active and leading role in formulating and designing tasks specific to their own child's needs and will be encouraged to implement and evaluate chosen tasks. Participants will receive regular researcher support to become independent in the management of their child's behaviours and practical skills to maximise and maintain child development/independence and enhance family relationships.

The major part of the research program will take place over an initial nine week period starting around early September, 2000. It will involve participation in weekly group training sessions, devising and implementing specific techniques for the participant's own child/child in their care (at home) and keeping regular records. Two individual follow-up sessions will take place within six months of the program ending.

Further comprehensive information is available by phoning the researcher: Robyn Hooper [phone number]. General inquiries welcome.

Research undertaken in order to fulfil partial requirements for a Doctor of Philosophy, Department of Education, University of Waikato.

Appendix B

Information for participants

Thank you for your inquiry regarding participation in my doctorate research. Please excuse the length of the following information but I feel it is vital that you are fully informed of the nature of the proposed research and participant requirements.

The major purposes of this study are:

- to conduct a program for parents/caregivers to manage the challenging behaviours associated with their child's Autism Spectrum Disorder,
- to maximise child development and family functioning,
- to evaluate the differences between two separate training components: - applied behaviour analysis and an autism-specific educative approach.

I am seeking to develop a short-term, intensive program for parents/caregivers of children with ASD to learn information and techniques specific to this condition. It is proposed that the development of specific skills will enable participants:

to reduce family 'stress' by improving understanding of the child's condition and why they do what they do,

to think about, plan and put in place specific methods designed to manage difficult or challenging behaviours associated with Autism Spectrum Disorders i.e., to become 'therapists' of their own child's behaviour and,

to increase and improve the range of adaptive living skills within the child's current behavioural repertoire in the areas of socialisation, communication and play/imagination.

Although there has been an upsurge in interest and professional knowledge of ASD over the past decade, studies have shown that parents of children with ASD are still left with a lack of resources and guidance and are themselves a relatively unstudied group. Investigations have shown that parents of children with ASD face higher 'stress' levels than almost any other disorder. A lack of available trained professionals has left parents/caregivers with feelings of helplessness, 'inadequacy' and a strong desire for knowledge and practical input to help with their child's condition and behaviour.

This programme was developed to fill a gap in available services as identified by parents of children with ASD. In consultation with you as parent/caregiver, target behaviours in the three core areas of ASD (i.e., a social, communication and interest range behaviour) will be identified as specific to your child. These behaviours will form the basis of focus for group discussion and individual practical exercises.

Parent training will take place in a small group session at a venue to be determined. A number of research measures including interview, rating scales and questionnaires will be recorded in your own home prior to the start of the group sessions.

Two programs will be run. Both have identical content but the order of presentation of information will be varied. Initial placement into a group will determine the order of training.
You will attend a total of nine training sessions over a nine-week period. Each weekly session will be two hours in duration with refreshments provided. During the group sessions, you will be taught to assess your child's behaviour, plan and put in place treatment outlines with guidance from the trainer. Finally, you will evaluate/discuss how you attempted the outline and the success of your approach. Between sessions (i.e., once a week), you will be required to undertake a behaviour-related homework task and keep daily records. The trainer will visit you in your home on a fortnightly basis for support and clarification as required.

After the fourth session (i.e., half way), some rating scales and questionnaires will be repeated so I can determine the effect of partial training. At the conclusion of the programme, these measures will be repeated again. You will also have an opportunity to comment on the group process/content and the value/worth of each training component.

Two other points of research contact will be made after the conclusion of the training programme (at 10 weeks and 6-7 months) to determine short and long term effects of the training process. Home follow-up sessions will include a short interview, a short-form behaviour record completed by yourself and repetition of the measures already outlined. It is expected that follow-up sessions will take no more than 2 hours each.

Confidentiality
Prior to commencement of the group sessions, all relevant information gathered from participants will be taken in confidence and coded to eliminate identification and to ensure anonymity. Group conduct (including confidentiality issues) will be determined by those attending. At any stage you can choose what information you wish to share/withhold in the group situation. All data collected during the course of intervention will be coded and raw data/information will be kept in a secure location in the researcher's home. This information will not be available to anyone without your express approval. The researcher adheres to professional Code of Ethics and this research proposal has been approved by the School of Education Ethics Committee – University of Waikato.

Safety of Participants

- There are no known or anticipated physical risks to participants partaking in this research project.
- The researcher has relevant postgraduate qualifications, practical experience and has received advanced training in behavioural intervention and applied behaviour analysis techniques.
- On a personal level, I am the mother of two boys, the elder of whom has an ASD.

Participant's wellbeing – adults:
Participants are strongly encouraged to bring a support person with them to all group sessions – this may be your partner/spouse, friend, relative, teacher aide etc. It is

expected that your support person will also know your child. The support person will NOT be the subject of any research procedures. They are there to support you and add their knowledge/perspective of your child to practical exercises and discussion if appropriate.

Groups will be structured to allow sharing of problems/stress and you will be encouraged to use practical examples of issues in regular group sessions. Participants are welcome to contact the researcher outside group sessions, however calls will be diverted through an answer phone outside set hours (to be determined at group session).

Participant's wellbeing – child/ren:
Children will not be observed without the presence of their parent/caregiver. Your child will not be the focus of direct intervention by the trainer. The trainer/researcher will provide group and individual instruction to yourself (as participant) so that you are able to implement behaviour change procedures by yourself. Potential negative behaviour changes (e.g., substitution of one behaviour for another or acceleration of behaviour rate/severity) will be clearly outlined to caregivers. Behaviour change/s will be closely monitored by the researcher and observed as necessary in conjunction with yourself. Throughout the period of this study, a strong consultative relationship with senior staff supervisors will be maintained by the trainer/researcher.

Through your own involvement, your child will also be participating in this study. As young children are legally unable to give informed consent for their participation in this study, such consent will be sought from their parents/caregivers. If you consent to your child's participation, we (the researcher and parent/caregiver) will attempt to inform the child (briefly and in age-appropriate language) of how they will be included in the study.

Participants' Right To Decline
The decision to participate will be yours/your family's, similarly, the decision to withdraw during the course of the study will be respected. All preliminary approaches will be in confidence and information pertaining to those who choose not to continue with the study will be destroyed.

Arrangements for Participants to Receive Information
Participants will have direct access to the researcher on a weekly basis (at group) and in-home sessions each fortnight. The researcher can be contacted by phone at other times (see above). Approximately 6-8 months after the finish of the programme, you will be invited to attend a feedback session. At this stage, you will be able to discuss the results of the research (to date). All participants will be offered a permanent copy of this analysis upon production and you can keep all relevant hand-outs/notes used/produced during the course of group work.

Use of the Information
It is envisaged that the study findings will be in a publishable form. One long-term aim of the study is the production and development of a socially valid and scientific

based group program that can be useful for other parents/caregivers. In terms of confidentiality and as already outlined no identifying information will be included in any form.

In summary, the purpose of the study is to empower you as parent/caregiver to act as 'therapist' i.e., you will learn the techniques and apply them within your own family situation. The techniques/skills learnt are considered supplementary to the range of parenting procedures that you already use. The role of the researcher is to guide and facilitate change through providing training in a specific set of applied behaviour techniques and providing ASD-specific information. It is not intended that the researcher assume the role of therapist, rather, the focus of the intervention is on you as 'therapist' for your own child. It is intended that you will learn techniques specific to *your own child* with Autism Spectrum Disorder and specific to the target behaviours *you* have identified prior or during the group intervention. Behaviour change in non-target areas is possible and will be noted as part of the follow-up process.

Finally please note the following potential conflict of interest:

The researcher is currently the Chairperson of the local branch of the Autistic Association of NZ Inc. While both roles are distinctive, I would like potential participants to be aware of this matter. There will be NO repercussions in terms of association matters for your participation or choosing at any stage to decline participation in this research. All matters pertaining to the research remain strictly confidential.

I will contact you shortly regarding your interest. In the meantime, if you have any queries or wish to clarify any of the above points, please do not hesitate to contact me.

Yours sincerely,

Robyn Hooper
Doctoral Student, School of Education, University of Waikato

Consent for Study Participants

Name:

Address:

Telephone Number:

I, , state that I voluntarily agree to participate in the research project conducted by Robyn Hooper, PhD student, Department of Education, University of Waikato as outlined below:

I understand the major purposes of the study to be as follows:

- To develop a short-term intensive group programme for parents of children with ASD to learn condition related information and practical techniques with the goal of managing challenging child behaviour, enhancing family functioning and maximising child development.
- To ascertain the effects of two differing treatment components (information versus functional applied behaviour analysis techniques).

I understand I will be required to:

- Attend nine consecutive weekly group sessions facilitated by the researcher
- Participate in group discussion and formulate an individualised intervention plan for my child in conjunction with the researcher and group members
- Administer the above intervention plan during the week following the session
- Observe and record behaviour changes (on parameters to be determined) on a daily basis and submit these records to the researcher on a weekly basis.

I acknowledge that Robyn Hooper has explained the task to me fully and has offered to answer any questions I may have about the research procedure. I have read 'limitations of the study' and have had my questions answered satisfactorily. I have been assured that any information that I give will be used for research purposes only and will be kept confidential. All identifying information will be removed and data encoded to ensure anonymity. I understand that I will set down guidelines for group confidentiality in conjunction with other group members at the first group session. At the conclusion of my participation in this study, I will be given information concerning research outcomes and any questions that I may have will be clearly and fully answered.

I have been informed of the nature of the research and the 'risks' and I agree to participate in the research as outlined above. I understand that I may withdraw from the study at any time or refuse to answer a particular question without penalty. In the event that I withdraw from the study, all personal data collected to that point will be destroyed and will not be used further.

I agree that my child; , may participate in this research project. In conjunction with the researcher, I have explained to my child that they are participating in research and I am satisfied that they understand their involvement to the best of their ability and development.

Signature of participant: Date:

Signature of researcher: Date:

This form is completed in duplicate. One copy is to be held by the participant and the other by the researcher.

NOTE: If you have any questions about the research, do not hesitate to ask the researcher (Robyn Hooper) or Professor David Mitchell (research supervisor). [Telephone numbers provided.]

Appendix C

Training Programme: *Recipe for Rainbows*

The following training programme is the trainer-version. Parts of the programme in square brackets are used to guide responses from participants. A simplified participant version of the programme was provided to parent-participant as a workbook. This second version is not presented here but is available from the author on request.

Recipe for Rainbows:

A Nine-Week Training Programme for Parents of Children with Challenging Behaviours Associated with Autistic Spectrum Disorder

Contents

SESSION ONE

Function of Behaviour

Behaviour has an effect. If it didn't, we wouldn't engage in certain behaviours. It has an effect on ourselves, others and the situation in which we find ourselves, however this does not mean that we deliberately and purposely set out to achieve these effects. Most of the effect of our behaviour is done without conscious thought or purpose.

Through the effects of our behaviour, we unconsciously communicate something to others.

This is particularly obvious when we consider negative behaviours.

Consider seeing a child throw a tantrum in the supermarket.
What is your first thought about why the child is doing this?
[to get something, to get their own way, tired etc].

Now what other possible reasons may there be for why this child is behaving like this?

Any one of these reasons may be the actual function of the behaviour or maybe not. There are many possible things a behaviour may be communicating to others.

Your initial thought about the reason for the behaviour is the 'communication' that you have picked up from the behaviour. It may be correct or way off the mark. However, if this is your belief about the behaviour, then you will respond accordingly and either give them what they want or adamantly refuse to! Generally our response is determined by the situation, our personal resources/parenting style and beliefs about the behaviour.

Now let's change tack slightly...

Think of a specific tantrum moment for your child:
What was the effect on you? [anger, embarrassment, dislike],
What was the effect on others? [avoidance, annoyance].
What was your response? Note the cyclical effect of these two factors. A lot of our reaction to negative behaviour is mediated by the perceived thoughts/feelings of others.

What was the outcome/effect for the child/situation e.g., did the tantrum result in a change in the situation for the child?

What was the outcome/effect for you/others?

The likelihood of this behaviour re-occurring depends on how well we have 'heard' what the behaviour is communicating and how well our response matches the communicative intent of the behaviour. More on this second point later.

Behaviour as a means of communication

We have already seen that one particular behaviour may be communicating any one of a number of functions. Now to add to the complexity of this matter - let us also consider that many behaviours look similar e.g., tantrums. Consider the tantrums discussed above – each of us will have had an expectation that we knew what the others were describing and why their child's 'tantrum' would be occurring.
Typical tantrum behaviours:

However, the motivation, situation and function of each may be completely different. So we are left with:

- Similar 'looking' behaviours may be communicating different matters and
- Any one behaviour may have a number of possible functions.

So how do we sort out the issue so we can start to alter problematic behaviour? We look for patterns.

[Scenario cards – Carr et al., 1994]

What happened before the problem behaviour?
What did the problem behaviour consist of?
What happened after the behaviour?

If we see patterns, we may attempt to determine the particular *function* of that behaviour i.e. what the behaviour is communicating (being used for).

The following are some typical functions of problem behaviour:

Approach	(attention)
Escape/avoidance	(from task, person etc)
Tangible	(want something/object)
Sensory	(like sensation)

If the behaviour is useful for the individual i.e. they get the desired outcome – the likelihood of the behaviour occurring is increased. The behaviour may not be 'socially acceptable', 'positive' or 'desirable' but it is the most effective way they have learnt to achieve their goal.

NB: there is often a strong relationship between problem behaviours and communication difficulties – ASD is defined by a triad of problems including communication difficulties.

NB: The fact that a certain behaviour has acquired a particular function is valid for the individual - the problem is *how* that need is communicated to others.

Functional behaviour approach - determining the function of the problem behaviour and then teaching a more appropriate behaviour that serves the same function.

The benefit of a functional approach to problem behaviour is that the child still gets their needs met but in a more appropriate manner for the family/others and in a manner which facilitates community acceptance and inclusion.

For example: If the function of tantrum behaviour is found to be attention, we find a more appropriate manner of getting the child to request attention by:
Changing the form of the behaviour (e.g., getting the child to verbally request attention) and/or
Changing the environment so more attention can be given to the child so they don't have to act up to get it (non-contingent attention).

Quite often we focus on changing the form of the behaviour and fail to consider that often the child's needs are valid and the problem is more one of environment including expectations of other's in the situation. This is particularly true with most approaches to child behaviour issues which focus on applying consequences.

Remember
- Behaviour can be viewed as a means of communicating/ telling us something.
- A number of similar looking behaviours may actually have very different underlying functions (or combinations of functions).

To attempt to control problem behaviour by applying a set of pre-determined consequences may actually make the situation worse. For example, if the function of a tantrum was to get out of the supermarket and we gave them a candy bar, the behaviour is likely to worsen in an attempt to get out. Similarly, if we sat them in the car for 'time out', they would have learnt that a 'tantrum' was an effective way to get out of the supermarket and would be more likely to engage in this behaviour in future.

Scenario Cards

NAME: Val		
Setting: Group instruction		
Before	**Behaviour**	**After**
Joan was asking each student in turn to identify some pictures from a magazine and to tell a story about each one	Val knocked the magazine out of Joan's hand and yelled 'you're stupid', to the student who had been speaking	Joan angrily told Val to pick up the magazine and tried to make her apologise to the other student. When Val refused, Joan persisted for 7 mins to try to get her to apologise.

NAME: Val		
Setting: Interval		
Before	**Behaviour**	**After**
The students were sitting on the grass near the playing field or walking around the courtyard. Joan was standing at the doorway talking to a male teacher.	Val ran up to the male teacher and yelled 'Hey nubbie!' in his face. When Joan tried to intercede, Val grabbed Joan's shirt sleeve and ripped it in the struggle that followed.	Joan severely berated Val for about 5 mins, telling her she should not interrupt when people were talking to one another and that she should apologise for ripping her shirt. The male teacher repeated many of Joan's comments to Val.

NAME: Val		
Setting: Lunch		
Before	**Behaviour**	**After**
Val was seated at the lunch table with some other students. Joan was putting the finishing touches on some birthday cupcakes for one of the students.	Val suddenly yelled "I'm not hungry". When Joan turned around and made eye contact, Val pulled the hair of the birthday student while staring at Joan. As Joan approached Val to protect the other student, Val spit at Joan, cursed repeatedly and tried to scratch Joan several times.	Joan pried Val's fingers off the other student and told Val she had better start acting more grown-up or nobody would want to be her friend. This theme continued for about 8 mins.

Scenario Cards

NAME: Gary		
Setting: Gathering Work Materials		
Before	**Behaviour**	**After**
Cal asked Gary to bring over a wheelbarrow full of potting mix to the workbench	Gary punched Cal in the chest and tried to punch him a second time in the face but Cal ducked.	Cal told Gary to "keep cool" and moved away from him. After a few minutes, Cal got the wheelbarrow himself.

NAME: Gary		
Setting: Potting Bulbs		
Before	**Behaviour**	**After**
Gary potted about 10 bulbs then stopped working. After 2 minutes, Cal said to Gary, "Come on, Gary, let's get on with the job".	Gary threw a pot at Cal and bit himself severely on the hand while jumping up and down on the floor.	Cal said to Gary "Calm down. Calm down. Everything's OK". After 5 minutes, Cal got out a soda and offered some to Gary.

NAME: Gary		
Setting: Planting Flower Beds		
Before	**Behaviour**	**After**
After 5 minutes of work, Gary slowed down his output to the point where he was putting in one plant every 2 minutes. Cal said to Gary "We have to pick up the pace a bit," and demonstrated the technique.	Gary grabbed a plant out of Cal's hand and tore it to pieces. Then, Gary grabbed Cal's shirt and ripped several buttons off it in the struggle that followed.	Cal disengaged himself from Gary and backed off about 10 feet. After 5 minutes, Gary calmed down. At that point Cal finished the planting by himself.

Scenario Cards

NAME: Juan		
Setting: Sitting in Backyard		
Before	**Behaviour**	**After**
Several residents are relaxing on lounge chairs eating snacks. Juan says "orn, orn" over and over again excitedly. Sam, a new staff member asks Juan "What do you want?, What are you saying?"	Juan runs at Sam and slaps him several times on the hands and arms. Then, Juan starts kicking Sam.	Sam backs away and says "It's OK, It's OK" to Juan. As Sam Moves about 5 feet from Juan, Juan suddenly runs by Sam and goes into the kitchen. He comes back with a bag of popcorn. Sam helps Juan open the bag and Juan becomes calm.

NAME: Juan		
Setting: Standing in the hallway		
Before	**Behaviour**	**After**
Juan, Bill and Sam are gathered in the hallway. Juan is pointing upstairs repeatedly. Bill and Sam ask, "What's wrong?"	Juan grabs Bill by the arm roughly and pulls him toward the stairs. When Bill resists, Juan hits Bill on the side of the head and screams several times.	Bill and Sam move away from Juan. Juan rushes past them and goes up the stairs to his bedroom. He returns calmly holding his favourite videotape.

NAME: Juan		
Setting: Watching Television		
Before	**Behaviour**	**After**
Juan is watching a TV program that he likes. Another resident enters and turns the TV to another station. Juan turns it back. The other resident turns the TV off.	Juan runs into the kitchen and pulls one of the staff members to the TV room while screaming. Juan kicks and slaps the staff member.	The staff member says "You'll be alright Juan. Calm down". Juan continues slapping. The staff member then turns on the TV and says "Look Juan, your favourite program. Now, will you calm down?" Juan stops slapping after about 5 sec and watches TV.

STEP 1:

Before attempting to change behaviour – we must attempt to assess the underlying function.

In order to do this, we must define the particular behaviour we are interested in and carefully observe it.

Practical Exercise: Take Behaviour 1

Define behaviour:

Describe what happened before, the setting, demands etc	What the behaviour was/what the child actually did	What happened afterwards e.g., reaction/outcome

What do you think the behaviour could be communicating/what do you think the function of the behaviour is?

Try answering the Motivation Assessment Scale (Durand, 1986 as cited in Durand, 1990).
What is the outcome?
Do they agree/disagree?

Notes:

Summary

It is important for us as parents to be able to feel our children's behaviour is reasonable and reasonably handled. ASD will affect our child's ability to function in everyday life and they may well express or communicate their frustration's/needs through their behaviour, particularly if they have impaired verbal skills! To minimise their distress/anxiety and maximise the likelihood that others will both approach/include them in the community – we can seek to explore the underlying function of their behaviour *before* seeking to change it.

The benefits of a functional approach to problem behaviour:

- We are more likely to get it right
- We are more likely to get it right first time!

This will lead to less child stress, increased child-parent trust, decreased family stress, increased family social life and increased learning opportunities for everyone.

Motivation Assessment Scale
(M Durand, 1986)

	Never	Almost Never	Seldom	Half the Time	Usually	Almost Always	Always
1. Would the behaviour occur continuously, over and over, if this person was left alone for long periods of time? (e.g., several hours)	0	1	2	3	4	5	6
2. Does the behaviour occur following a request to perform a difficult task?	0	1	2	3	4	5	6
3. Does the behaviour seem to occur in response to your talking to other persons in the room?	0	1	2	3	4	5	6
4. Does the behaviour ever occur to get a toy, food, or activity that this person has been told that he/she can't have?	0	1	2	3	4	5	6
5. Would the behaviour occur repeatedly, in the same way, for very long periods of time, if no one was around?	0	1	2	3	4	5	6
6. Does the behaviour occur when *any* request is made of this person?	0	1	2	3	4	5	6
7. Does the behaviour occur whenever you stop attending to this person?	0	1	2	3	4	5	6
8. Does the behaviour occur when you take away a favourite toy, food or activity?	0	1	2	3	4	5	6
9. Does it appear to you that this person enjoys performing the behaviour? (It feels, tastes, smells, looks and/or sounds pleasing)	0	1	2	3	4	5	6
10. Does this person seem to do the behaviour to upset or annoy you when you are trying to get him or her to do as you ask?	0	1	2	3	4	5	6
11. Does this person seem to do the behaviour to upset or annoy you when you are not paying attention to him/her?	0	1	2	3	4	5	6
12. Does the behaviour stop occurring shortly after you give this person the toy, food, or activity that he/she requested?	0	1	2	3	4	5	6
13. When the behaviour is occurring, does this person seem calm and unaware of anything else going on around him/her?	0	1	2	3	4	5	6
14. Does the behaviour stop occurring shortly after (1-5 mins) you stop working or making demands of this person?	0	1	2	3	4	5	6
15. Does the person seem to do the behaviour to get you to spend some time with him/her?	0	1	2	3	4	5	6
16. Does the behaviour seem to occur when this person has been told that he/she can't do something that he/she wanted to do?	0	1	2	3	4	5	6

Sensory	Escape	Attention	Tangible
1. _____	2. _____	3. _____	4. _____
5. _____	6. _____	7. _____	8. _____
9. _____	10. _____	11. _____	12. _____
13. _____	14. _____	15. _____	16. _____

Total Score= _____ _____ _____ _____

Mean Score= _____ _____ _____ _____

Ranking= _____ _____ _____ _____

STEP 2:

Teaching a more appropriate behaviour which will provide the same functional or communicative outcome for the child.

In order to consider this next step, it is first necessary to consider what we are already doing and clarify some common misconceptions about how we actually alter behaviour in general.

Rewards/Punishment

Common parent training approaches focus on when and how to assert our authority and how to 'discipline' our children effectively. As parents and caregivers, we have been led to believe that successful behaviour management depends on effective consequences being applied to particular behaviours. To increase 'good' or 'desirable' behaviours, we reinforce or reward, to decrease 'negative' or 'undesirable' behaviours – we punish.

Rewards ⟶ Increases (or maintains) behaviour

Punishment ⟶ Decreases (or eliminates) behaviour

However, this approach is backwards. It focuses on the consequences of behaviour and leads us to think that we can develop a set of punishments and/or rewards that can be used to control any behaviour.

As an alternative, consideration of the underlying *function* of the behaviour requires us to 'listen' to the communicative intent of the behaviour. With this information, we are able to devise a response that considers the child's skills and the demands of the situation at hand. We are more likely to effect positive and long-lasting behaviour change without resorting to aversive techniques or adding stress to the parent-child relationship.

If a behaviour exists or increases (it has a function) – it is being rewarded. If a behaviour decreases or disappears (it has lost its function) – it is being punished.

Rewards/punishers are determined by their *effect on behaviour*, they do not consist of two categories of set items. If something increases behaviour, it is called a reward/reinforcer. If something decreases behaviour, it is called a punisher.

	Apply/give something (Positive)	Take something away/remove (Negative)
Behaviour Increase/ or maintained	Positive Reinforcement	Negative Reinforcement
Behaviour Decrease/ or disappears	Positive Punishment	Negative Punishment

What we consider 'punishment' is not necessarily – it depends on the effect on the target behaviour.

Because a behaviour is considered problematic, it is occurring/exists and therefore is serving a function for the individual. If a behaviour continues to have a function – it is being rewarded i.e., there is some positive effect of the behaviour for the individual in terms of self, socially (others) or the situation. This may or may not be apparent to the individual or any others in the situation!

Consider a typical problem: **Disruption in class**
Typical solution: **Sent out of the room**

What is the intent here? [*Punish behaviour/decrease*]

How will this be achieved?

- By removing social reinforcement
- By removing from task they presumably enjoy
- By using socially negative consequences e.g., peer pressure etc

Outcome: Disruptive behaviour continues.
Behaviour is continuing so it is being reinforced/punished?

Possible reinforcers?

- escape from workload or tasks considered too difficult
- something interesting in the corridor
- escape from sensory overload/stimulation
- sent to see someone they particularly like (even if encounter is negative!)

Possible functions of the behaviour?

- Work too hard
- Want to do something else/bored
- Sensory overload

Do they match?
What is the outcome for a mismatch?

The dangers of having a consequence-focus when approaching behavioural issues are evident. Using a pre-determined set of punishment and rewards is detrimental to both the child and your relationship with him/her. Failing to consider the function underlying a particular behaviour is the major reason why people experience failure in trying to change behaviour and why many end up giving up trying or feel that behavioural 'techniques' don't work.

Notes:

1. Outcomes can get complicated i.e., the behaviour may decrease but the function may change, the behaviour may decrease but for the wrong reason and so may reappear later or the same solution won't work next time etc.
2. We are not so much interested in trying to determine the cause of the behaviour because often the original causes are not available to us and when they are, we often cannot change them.
3. Situations can change reinforcer/punisher values. For example, to give a child an ice cream when the child is ill is not reinforcing at all!. However, consequence based parenting is the most commonly taught method available today.
4. This is not a 'normal or automatic' way of thinking about difficult behaviours.

Our knowledge of our child and his/her condition is often disregarded in the face of cultural and societal 'norms' and expectations. For example, in our society and culture, we expect certain things to be rewarding (e.g., treats/social contact). The expectation that social isolation may therefore be punishing (because it is for most children) may be severely flawed when applied to individuals with ASD and the behaviour may be exacerbated instead of declining.

The functional approach to behaviour gives us a focus and plan for effective behaviour change. Rather than repeatedly trying multiple methods to control behaviour, we could learn to focus on what the behaviour could be trying to 'tell' us.

Homework Exercises:
Work on Behaviour 1 only.

1. Observe and record behaviour – Use 'before, behaviour, after' records.
(Continue to monitor all behaviours as previously decided between you and trainer).

2. Consider your current management strategies for this particular behaviour – i.e., what do you currently do for this behaviour? How do you respond? What is your intent? How successful is it?
What other outcomes of the behaviour could be reinforcing (and therefore maintaining) the behaviour?

Exercise 1:

Date/Time	**What happened before?** What was the child doing: who else was around/involved: what else was going on in the setting: where was the child?	**Describe the behaviour.** What did the child actually do?	**What happened next?** What did you/others do? What did the child do? How did the setting change?

What is/are the possible functions of this behaviour?

Exercise 2:

	Apply or give something	Take away or remove something
Behaviour Increase	Positive Reinforcement	Negative Reinforcement
Behaviour decrease	Positive Punishment	Negative Punishment

Setting	Current management strategies for this behaviour?	Where does it fit on the reward/punishment chart? Your intention…	On a scale of 1-10: how successful is it? (1= nil, 10=very successful)
	e.g., put him in his room	*Negative reinforcement*	*4*
Home			
School/ preschool			
Community e.g., socialising, supermarket etc			
Other			

Consider the function you have outlined from your observations this week: Which management strategies would not appear to have a successful outcome and why?

SESSION TWO

Functional Communicational Training

Functional Communicational Training consists of two components:

1. Teaching an equivalent functional behaviour
2. Making the problem behaviour non-functional

Determination of functionally equivalent behaviour

Once we have determined the function of the problem behaviour to the best of our ability and understanding, we then turn our attention to finding a behaviour that can result in a similar/same function for the individual but this time, the behaviour will be non-problematic/socially acceptable and reasonable for both the family and child.

Before proceeding, it is necessary to first consider the goal behaviour.

What is the goal behaviour?:

1. *Is the goal behaviour age appropriate?*

2. *Are the materials/activities needed to perform behaviour present in immediate environment?*

3. *Does the child have the necessary skills to perform the new behaviour?*

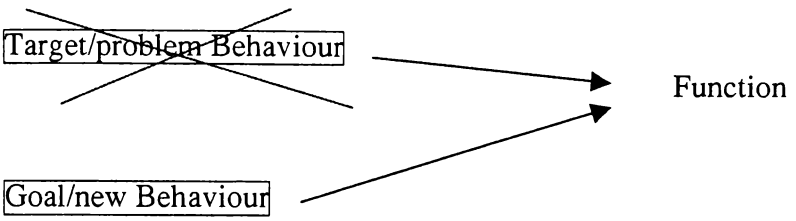
4. *Does the behaviour make the child more independent?*

5. *Does the behaviour prepare the child to function in community environment?*

Once the goal behaviour is decided and the above questions answered satisfactorily, we can turn our attention to the new/replacement behaviour.

The focus is on the identification of a behaviour that will most likely provide the child with the types of functions currently being provided by the problem behaviour.

E.g., if the problem behaviour had the function of eliciting attention, then the new behaviour should also provide the child with attention.



Function of current behaviour: New Behaviour:

NB: There may be more than one function behind a problem behaviour and functions can change over time and once intervention has begun.

The new behaviour must be more efficient for the individual i.e. be easier to perform, gain faster or larger outcome etc. This can be achieved by consistent reinforcement of desirable behaviour and faster reinforcement i.e. no time delay between desirable behaviour and response.

Guidelines for Communication Training or Training New Behaviour

View problem behaviour as a *skills deficit* on the part of the child. They have learnt the best way they know how to achieve the current effect, now they need you to teach them a new skill (it is not a part of their 'mischievous' or 'bad' personality) *and a possible environmental deficit* (a problem with the prevailing environment/setting).

- Set up situation so the child engages in as few errors as possible i.e., give maximum opportunities for desirable behaviour and few opportunities for undesirable behaviour.
- Train child in expected desirable behaviour – perform expected behaviour in front of your child, make sure other family members have consistent behaviour, prompt your child for the correct response.
- Consider the setting in which the problem behaviour is taking place – does it/the people involved have to change?
- Start small!

Practical exercise:

Function of current behaviour:

Functionally equivalent response: What other behaviour/s will allow my child to get the same function as the above behaviour?

Errorless learning: How do I set up the situation so my child can engage in lots of new behaviours and few old/problem behaviours? (What sort of things can set them off?)

Training technique: (e.g., model behaviour yourself, prompt child to engage in new desired behaviour, hand over hand, physical direction etc)

Is a new behaviour required which needs to be taught in steps? (See hand-out)

Setting: What things need to be changed in the setting/environment where the behaviour occurs to help my child engage in the new behaviour? What changes do the people in his/her environment need to do differently?

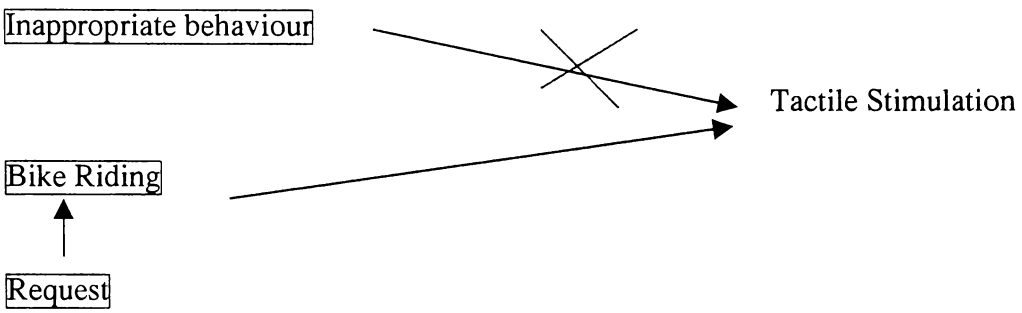
Functional training should have implications for both the communicative response being taught and the environment/setting. This problem did not arise simply on the child's part.

NB: There is often a fear that if a child is given more of something that they want, they will simply come to expect them more and more and therefore request them all the time. Much to the surprise of all, this doesn't happen! If the function of a behaviour is purely motivated by a desire to get an object (etc), more access to the object will not cause the child to continually request it.

Sensory Function: This is perhaps the trickiest of all behaviours to try and change because the consequences of the behaviour are not easily accessible or available for others to change.
Consider rocking or hand-biting/self-mutilation. We do not want to replace these behaviours with others which also reinforce self-harm. However, focusing on the function of the behaviour, we do have a means of changing it.

For example: If the rocking is giving a pleasant tactile sensation, we may aim to replace rocking with another behaviour designed to give tactile sensation e.g., riding a stationary bike or other sport-oriented behaviour. In one case (from a research study), the individual had to first be trained how to use a stationary bike and initially he was resistant to the change. However after persevering for a couple of weeks, he was happily using it and it had replaced a previously disruptive and inappropriate behaviour. In this case, once the new behaviour was established, the individual was taught to request it as/when he wanted. Despite fears that he would spend most of his time on it – he did not. He happily engaged in his work duties and moreover, the problem behaviour completely disappeared.

Why? The problem behaviour was replaced by another behaviour which fulfilled the same tactile sensation (function). As he had access to bike riding on *request,* he did not have to engage in difficult behaviour.



If we want the child to wait for a while before receiving the request/reward, we need to teach this too *after* we have successfully established the new behaviour. Star charts and stop/go (red/green) signs have been useful for this purpose.

Making the other behaviour non-functional

As we have already outlined last week, most parent training programs rely heavily on teaching the consequences to undesirable behaviour

e.g., tantrum ⟶ Time Out/other punishment

or reward other positive behaviour e.g., not tantruming. This idea may have limited success if the function of the desirable and undesirable behaviours is not equivalent.

e.g., tantrum	Function: attention
Not tantruming	Functions: varied – may be gaining attention, may be interested in subject/activity, may be engrossed in something separate from activity, may be tuning out etc

We aim to help our child understand that the target/problem behaviour will no longer have an effect on the environment.

HOW?
What is the function of the target behaviour?

What is the current effect of the target behaviour? (on the setting, activity, people involved?)

Now we act as if the behaviour were not occurring, i.e., we lose the effect/function:

This is NOT the same as ignoring. Ignoring is often 'done incorrectly' and can in itself change the dynamics of the situation. Consider the situation where a child's behaviour is motivated by attention. One would think that ignoring would decrease the behaviour because the function is no longer being met – but the teacher etc gets up and removes the child or they ignore them and then berate them when the 'ignore' period is up. Bingo! The child has got attention.

- This is not easy especially if the child is being disruptive. One method may be to guide them to their bedroom etc while still maintaining the conversation or activity you were doing i.e. don't talk to the child, don't react/facial expressions, don't give them the 'evil eye'. Limit discussion beyond restating 'rule'. Return to prior activity.

There are guidelines:

- Protect the child from harm. Protect others from harm
- Do not react to the problem behaviour per se

Your method of reacting to problem behaviour will depend on your own personal style. Remember, the aim is to not reinforce or reward (inadvertently) the effect of the negative behaviour on the environment. Accompany this with teaching your identified equivalent response.

Practical exercise:

What do you currently do or what happens in the environment now when your child engages in the target behaviour? Use 'after' part of record sheets.

Develop a policy for dealing with the target behaviour (part II). Your aim is to try to eliminate the effect of the target behaviour on the environment.

Plan for Functional Communication Training

Name:
Target Behaviour:

Goal Behaviour/functionally equivalent:

How I will achieve this:

How I will make the target behaviour non-functional:

Homework:

1. Implement the above plan for behaviour 1.
2. Record on a daily basis as before but this time add when you used this plan.
3. Start recording 'before, during, after' records for behaviour 2.

Teaching New Behaviour

At some stage we will need to teach our child some type of new behaviour. This may be as part of our plan to increase or introduce a new/desirable behaviour or to increase self-help skills to aid independence.

Opportunities to teach new behaviours should be incorporated into natural teaching situations: e.g., teach the child how to dress themselves when they are getting dressed.

Objectives:
- To let child experience success
- Reward attempts that approximate new behaviour or skill
- Let child have some choice
- Reduce opportunities for error.

Techniques:

1. Shape desired behaviour by breaking the new task into steps and reward successful completion of each. NB; The number of steps required will depend on the child.
2. Use prompts or graduated guidance:
   a. Most to Least – begin with prompting the completed task and work backwards (dress the child completely except for last item of clothing, once successful at putting on that item, leave last two items for them to complete…)
   b. Least to Most – begin with initial prompt and work up to full task (get them to put on first item and help them complete the others, once successful – get them to put on two items and then complete others…)

The choice of technique depends on the child and the task. Err on the side of simplicity and choose the technique which allows for the least errors possible. If you start too simply, you can easily move quickly through the steps. If you start too hard, the child may find the task too difficult or frustrating and give up.

Once the new behavioural steps have been successfully established, remove the prompts for that stage. Try not to go backwards and re-prompt previously successful steps.

Plan for Teaching New Behaviour

New/goal behaviour/skill:

Goal task:

Break task down into steps:

1.
2.
3.
4.
5.
6.
7.
8.
9.
10.

(Where a more complex task is desired, a number of separate tasks may be required first e.g., getting one's breakfast assumes one can already find necessary utensils and food and know how to butter toast, pour drink etc.)

How can I incorporate this teaching in a 'natural' situation?

How will I increase the desired behaviour (reinforcement)?

How will I make the function/purpose of this new behaviour clear to my child?

Break task down into steps:

1.
2.
3.
4.
5.
6.
7.
8.
9.
10.

Monitoring Sheet

Task Step	Dates/attempts													
1.														
2.														
3														
4														
5														
6														
7														
8														
9														
10														

SESSION THREE

Functional-ABA Approach to Behaviour

Behaviour 1:

Feedback outcomes of implementing homework plan per person.
Discuss/note

- behaviour change/new behaviour
- effect on child, others, situation
- family reactions including child
- total incidences of target behaviour – decreasing?

Collect behaviour 1 monitor/record sheets

Behaviour 2:

Discuss observation sheets for behaviour 2.

Individually formulate possible functions for behaviour 2. Use summary exercise MAS as needed. Increase/decrease behaviour.

Collect record sheets

Group sharing/feedback

Individually formulate plan/policy.
Including: Determine goal behaviour
Determine equivalent function
Teach behaviour to give desired response
Make other behaviour non-functional
(Summary forms from session II).

Share as a group.

Homework:
Continue to monitor behaviour 1 and 2.
Implement behaviour plan 2.

HANDOUT: Behaviour 2 – Functional-ABA Approach

Practical exercise:

Function of current behaviour:

Functionally equivalent response: What other behaviour/s will allow my child to get the same function as the above behaviour?

Errorless learning: How do I set up the situation so my child can engage in lots of new behaviours and few old/problem behaviours? (What sort of things can set them off?)

Training technique: (e.g., model behaviour yourself, prompt child to engage in new desired behaviour, hand over hand, physical direction etc)

Is a new behaviour required which needs to be taught in steps? (See hand-out)

Setting: What things need to be changed in the setting/environment where the behaviour occurs to help my child engage in the new behaviour? What changes do the people in his/her environment need to do differently?

HANDOUT: Making the other behaviour non-functional

We aim to help our child understand that the target/problem behaviour will no longer have an effect on the environment.

Practical exercise:

What do you currently do or what happens in the environment now when your child engages in the target behaviour? Use 'after' part of record sheets.

Develop a policy for dealing with the target behaviour (part II). Your aim is to try to eliminate the effect of the target behaviour on the environment.

HANDOUT: Plan for Functional Communication Training – Behaviour 2

Name:
Target Behaviour:

Goal Behaviour/functionally equivalent:

How I will achieve this:

How I will make the target behaviour non-functional:

SESSION FOUR

Functional-ABA Approach to Behaviour

Behaviour 2:

Feedback outcomes of implementing homework plan per person.
Discuss/note

- behaviour change/new behaviour
- effect on child, others, situation
- family reactions including child
- total incidences of target behaviour – decreasing?

Collect behaviour 2 monitor/record sheets

Behaviour 3:

Discuss observation sheets for behaviour 3.

Individually formulate possible functions for behaviour 3. Use summary exercise p2. MAS as needed. Increase/decrease behaviour.

Collect record sheets

Group sharing/feedback

Individually formulate plan/policy.
Including: Determine goal behaviour
Determine equivalent function
Teach behaviour to give desired response
Make other behaviour non-functional
(Summary forms from session II).

Share as a group.

Homework:
Continue to monitor behaviour 1,2 and 3.
Implement plan for behaviour 3.

Repeat baseline measures during week before session five – midpoint recordings.

HANDOUT: Behaviour 3 – Functional-ABA Approach

Practical exercise:

Function of current behaviour:

Functionally equivalent response: What other behaviour/s will allow my child to get the same function as the above behaviour?

Errorless learning: How do I set up the situation so my child can engage in lots of new behaviours and few old/problem behaviours? (What sort of things can set them off?)

Training technique: (e.g., model behaviour yourself, prompt child to engage in new desired behaviour, hand over hand. physical direction etc)

Is a new behaviour required which needs to be taught in steps? (See hand-out)

Setting: What things need to be changed in the setting/environment where the behaviour occurs to help my child engage in the new behaviour? What changes do the people in his/her environment need to do differently?

HANDOUT: Making the other behaviour non-functional

We aim to help our child understand that the target/problem behaviour will no longer have an effect on the environment.

Practical exercise:

What do you currently do or what happens in the environment now when your child engages in the target behaviour? Use 'after' part of record sheets.

Develop a policy for dealing with the target behaviour (part II). Your aim is to try to eliminate the effect of the target behaviour on the environment.

HANDOUT: Plan for Functional Communication Training – Behaviour 3

Name:
Target Behaviour:

Goal Behaviour/functionally equivalent:

How I will achieve this:

How I will make the target behaviour non-functional:

SESSION FIVE

Social Understanding
Theory of Mind

You can teach your child communication and social skills but often these skills do not generalise to other settings or they have a limited period of effectiveness for the child before they revert to previous behaviours or develop into further undesirable behaviours.

An understanding of the nature of ASD can provide a unique direction when dealing with problem behaviours or lack of skills.

Many intervention programmes that focus on specific behaviours have little success due to a failure to recognise that the features of ASD have a profound impact on the assumptions underlying behaviour 'modification' or change.

For example, let us consider a problem common to individuals with an ASD - lack of appropriate eye contact.

> *"My son won't look at people when he greets them/talks to them/when they talk to him".*

We can fix this (if punishment and rewards are strong enough) but the problem is...it won't be very successful (behaviour will be inflexible, inappropriate) because of a lack of consideration of the assumptions underlying *why* we should look at others.

Let's break it down...

Why do we want Joey to look at others?

- to facilitate interaction: gain information/knowledge
- to acknowledge others: polite/respectful, says good things about ourselves
- to see their reaction: infer what we see will give us knowledge about other persons feelings etc so we can predict their behaviour and interact appropriately.

What is 'normal' for us in terms of eye contact?

What do we get from eye contact?

NB: Eye contact is seldom used without other accompanying body cues

What else can we convey with eye gaze?
Very subtle, but we use eye contact to convey feelings, desires and are able to infer what is going on in someone's head (hostility, love, sad...)

- Anger: stay away, give me space, flee, watch out, danger...
- Friendship/love: approach, caring
- Attention
- Scared/sad
- Misunderstanding/understanding

Not only is *what* we convey by eye gaze variable but so is *how* we use it. If too long – uncomfortable (receiver feels uncomfortable – lacks power), if too short, we feel the sender is hiding something - we attach negative connotations attached to sender.
Eye gaze use also depends on the context of situation and the relationship between individuals. NB: also cultural, societal, gender issues.

We have been able to answer all the above questions based on our automatic understanding of social interactions and behaviour.

Exercise: Use Behaviour 1

What is the current behaviour of interest?

What behaviour would you prefer?

Why? What benefits are there to the child/others?

What is our social understanding of the importance of this behaviour?

We want our child to be liked, gain information, facilitate social interactions. We have good reasons for wanting to change this greeting behaviour, but if we focus on the behaviour itself, we will only make limited gains and the behaviour will become inflexible and unnatural.

A focus on developing key aspects of the social understanding underlying problem behaviours (as opposed to a focus on the specific behaviour of interest) will result in more wide spread change in social behaviour.

Realise: Our social understanding is one thing – we are surrounded by similar-minded people. But the social understanding of individuals with an ASD is quite another.

Theory of Mind

Key deficits in social understanding are a principle feature of Autism Spectrum Disorders. Individuals with an ASD have an incomplete ***Theory of Mind***.

[Give a number of pictorial scenes – ask group to explain what is happening and why – NB; inferences and cues used to arrive at this information. In stories and advertising, we can follow various complex interactions and understand relationships between characters].

Theory of Mind = the ability to mind-read.

Having a theory of mind means that we have the ability to 'mind-read'. We know that we have thoughts, feelings, beliefs and desires and we know that other people have these mental states too. We can use this common information to infer/interpret/predict or make sense of their actions and what they will do next.

In order to gain an insight into the world of the individual with an ASD, we need to first consider the path of usual development...

Usual Development:

We have been developing an ability to mind-read since birth and by age 4-5 years, it was basically complete.

Babies can react appropriately to facial gestures. They can follow eye gaze – indicating that they know they will find something worth looking at or informative by following another person's lead. This skill progresses to pointing – sharing information by gesture. By the time toddlers speak (18-30 months), they can correctly refer to a range of mental states (thoughts, emotions, desires (I want...), beliefs, pretence etc). By age 3-4, the ability to mind-read is well developed. Children at age 4 years can understand false belief. For instance if they *know* the money is in the jar but Burglar Bill *thinks* it is in the drawer they understand that Burglar Bill will look in the wrong place (i.e. the drawer). So they enjoy surprise, suspense, develop anticipation and can devise and enjoy comedy and practical jokes.

[Sally-Ann task]

False belief tasks are complex because they involve being able to consider a situation from the knowledge and belief system of another person, even though the situation is

wrong or false. For example, Sally didn't *see* the ball being moved, therefore she won't *know* it was moved and so she will *believe* it was still in the original place (in the cup). By understanding false beliefs, we would know that Sally would now *look* in the 'wrong' place i.e., we can predict and explain her next behaviour.

At much earlier levels of age, young children (age 2) are well aware that:-

People have information in their heads (informational states), they have the ability to infer *what* another person can see (thus, they can put things in and out of sight of another person on request). At age 3-4 years, they develop the ability to infer *how* an object appears to another and thus are gaining the idea that people hold different perspectives of the same item.

[Card Task]

Another development in the area of mind-reading is a child's understanding that *seeing leads to knowing.* A 3 year old can easily determine which of 2 people will *know* what is in the container if one simply touched it whereas one person looked into it. Thus they know that *access to information helps us acquire knowledge.*

Summary:
Beliefs/what we think:
- People have information in their heads
- Ability to infer *what* another person can see
- And *how* another person sees it (perspective)
- Seeing leads to knowing → access to information helps us acquire knowledge

Desire is another key mental state. If we add knowledge of a person's desires/wants to knowledge of their belief's – all behaviour becomes interpretable. For example, why would the man tiptoe into his own darkened flat?

➢
➢
➢

We can infer beliefs/desires by the context of the situation, by the facial expressions (i.e., the emotion/informational state) or gestures of the person (and others) and by our previous knowledge of or experience with similar circumstances.

While very young children (and those with an ASD) can correctly identify and label simple emotional states, by age 3 years most 'typical' children can also determine how the situation affects emotions and by age 4, they can take into account someone's beliefs and desires in understanding/predicting how they will feel.
e.g., John wants a new book but thinks he is getting a jersey → sad.

Summary
Desires/wants:
- Belief + desire = predictable behaviour/explainable behaviour
- Situation affects emotion
- Beliefs/desires affect emotion

Pretend play begins to develop at age 10 months and at this age, an infant can clearly recognise the *real* function of 2 separate objects but can also *pretend* one is the other e.g., banana and telephone. If your child takes their cues from the real world and is not able to understand *pretence* as an abstract/mental act, what would you expect to see in their play?

-
-
-
-

[one would expect to see stereotyped, repetitive or delayed, absent play.]

Benefits of Social Understanding

➢ **Able to understand human world**

How often have you come home and regaled everyone with your experience with a rude shop assistant? Unexpected negative behaviours affect our emotions and behaviour (we talk about it). It also affects our future behaviour (going back to that store). Empathy, persuasion, self-reflection – all rely on an understanding of our own mental states relative to others.

➢ **Able to formulate explanations about behaviour and predict next behaviour.**

By and large, we make these evaluations automatically and move through our days/lives without much thought about such matters and by and large, people are predictable and we do not expend energy or emotion about daily occurrences.

Consider passing an individual cheerfully whistling as they walk down the road towards you. Now imagine if they walked into the nearest shop, pulled out a gun and shot innocent bystanders.

How would you feel?
[shocked, devastated,...]

Why?
[unexpected, not normally what you would expect...]

We would have lots of explanations in hindsight (NB: desperate and natural attempt to put the world into explainable order) but you would never have been better prepared or able to predict what was about to happen.

What would be the immediate ...
[scream, run away...]
and long-lasting effects of this situation?
[anxiety, distrust of others/self...]

How would your behaviour look to others if you had to deal with these types of anxieties and misunderstandings on a daily basis?

This is the world of someone who cannot understand or predict the behaviour of others: the individual with an ASD.

Whereas such situations will hopefully never occur in our lifetimes, the person with an ASD faces an unpredictable world like that every day.

Another function of mind-reading is the:

- **Ability to understand communication because we can determine the meaning or intention of the speaker even if not conveyed in words.**

"Today we are going to paint the rabbit in his cage"

We know that the intention here is that we paint a picture NOT the rabbit. However, our language is usually far removed from the meaning that we intend to convey. ["I think that Isaac needs to let off some steam" = go outside with him and let him kick a ball or do something physical]

NB: the problems this causes naturally between men and women/partners etc!

Successful communication means less about understanding the actual spoken words and more about understanding body language, cues, expressions, context, previous conversations etc. We can successfully interpret gestures in the absence of words altogether e.g., come here, enter, stop...

Successful communication also means that the speaker can monitor the listener's state;

- Does Joey already know this?
- Do they want to know?
- Are they understanding what I'm saying?
- Am I going too fast/slow?

All these features of mind-reading normally develop spontaneously in childhood. If you take 5 years off your age, that's how long you've been on autopilot with respect to mind-reading and why it is extremely difficult for us as adults to consider what it must be like without this 'innate' ability. Individuals with an ASD have major difficulties with mind-reading and these difficulties underlie many/all of the characteristic behaviours, communication and play features of autism.

Moreover, difficulties in this area are **unique** to ASD. No other developmental disorder shares the same 'mind-blindness' features.

Individuals with ASD have difficulties:

- Understanding the human world
- Understanding and formulating behaviour and predicting the behaviour of others
- Understanding what others want or believe
- Understanding the meaning behind communication

This means that the individual with ASD can be:

- Insensitive to the feelings of others
- Unable to take into account what others do/don't know
- Unable to negotiate friendships by reading/responding to intentions
- Unable to read listener's level of interest
- Unable to detect speaker's intended meaning
- Unable to anticipate what other's may think of one's actions
- Unable to detect/respond to misunderstandings
- Unable to deceive/persuade or understand deception/persuasion
- Unable to understand the reason's/intentions behind people's actions/behaviour
- Unable to decipher 'unwritten' rules or 'social norms'.

NB: Some individuals with ASD pass initial stages of mind-reading but all generally have major difficulties with more complex stages particularly in the area of beliefs. However, they can be taught some degree of social understanding. We have to teach our children those things that we take for granted and that we expect them to pick up 'naturally'.

The blind use braille (sensory input) as an alternative way to problem solve. People with autism/ASD need to be taught an alternative cognitive pathway in order to problem solve. However, before attempting to change their understanding, we need to understand the individual.

Homework: Observe target behaviour over following week.
Use diary sheets:

- What happened before the behaviour? What was said? (exact words – don't change anything/summarise)
- What did the individual do (describe behaviour).
- Your reaction/consequence.
- What are the consequences of this behaviour for child, you, others, situation?

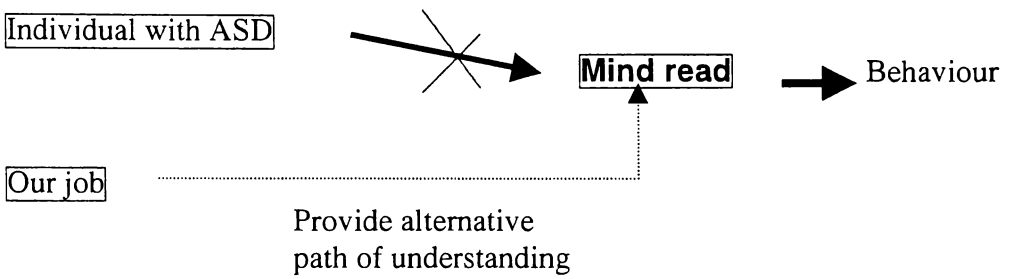
Exercise 1:

Date/Time	What happened before? What was the child doing: who else was around/involved: what else was going on in the setting: where was the child?	Describe the behaviour. What did the child actually do?	What happened next? What did you/others do? What did the child do? How did the setting change?

SESSION SIX

Social Understanding & Teaching Emotion/Beliefs/Desires

Difficult behaviours are often a result of the child's inability to understand their world. We live in a very different, predictable world thanks to our innate ability to understand social situations and expectations. Our children inhabit this same world but it is totally unpredictable to them. In response, they move through their days/lives in a perpetual heightened sense of anxiety/awareness and seemingly little things may push their tolerance over the edge. Rather than letting them wander about in this state (not knowing what to do, what is expected of them, what is going to happen next), we can aim to avoid difficult behaviours by giving the child some extra tools to help them approach tasks confidently and with optimal chance of success.



We have to make the mind-reading process *explicit* for our children rather than relying on them to develop an in-built ability.

How?

In order to determine how a lack of social understanding (or ability to mind read) may be contributing to the target behaviour, it is first necessary to examine the behaviour itself...

Recall from the exercise in last week's session. Target behaviour:

Now consider your first before/during/after scenario from your homework exercise:

- *What did you intend to happen/your child to do in this situation?*

- *What did you actually say? And how did you say it?*

- *What are the unspoken social expectations?*

How can we make this meaning more explicit (as opposed to relying on our child to 'pick it up')? i.e., how do you make what is in your head more accessible to your child?

[Handout – discussion]

Consider:
- Did we adequately signal beginning/end of task?
- Did we prepare for change?
- Can we break down the situation to facilitate understanding?
- How do we make the child aware of the meaning/intention/ expectations of the task?
- Simplify language
- Use precise language
- Use multiple methods of reinforcing message e.g., visual, written, spoken etc.
- Explain/use visual aids to detail situation
- Explain to the child what behaviours are required of them. Use rules as necessary to avoid 'grey' areas.

You may have to do some skill-building first e.g., teach emotional responses, beliefs, desires (see separate sheet).

During

Using your homework scenarios allows us to work with the benefit of hindsight. You will not be able to avoid difficult behaviours all of the time, so don't berate yourself for such scenes! Use these times as learning situations.

After
Practice in all situations that produce difficult behaviour, even in hindsight – AFTER the scene and once you've had time to work through it. If you don't understand at the time, make a note of it and go back over the questions in Box 1 later when you've got some time to think it through.

Look at the other scenarios you have recorded. Are there patterns emerging? What does your child's behaviour show you about your child's level of understanding - before and after? (i.e. was the instruction clear and did your reaction after the behaviour clarify things for your child?)

When presenting your child with a *new situation* - we can lessen the amount of anxiety they experience by preparing them with a little forward planning.

- Plan activity in advance
- Make sure the activity/ies are engaging for child or else plan to include an activity for child in situation.
- Involve child in activity.
- Use natural/incidental teaching.
- Answers child's questions.
- Clarify/summarise and restate rules.
- Praise, apply practical consequences.
- Stick to what you decide to do!

Exercise: Plan

Go back over the scenarios you did for homework.

- What did you want/intend?

Aim: What is my intention? And how do I help my child understand this intention and experience a successful outcome? If an undesirable outcome occurs - how can I use it to further my child's understanding?

- Decide on a plan of action in terms of preparation, words to be used etc. for prompting desirable behaviour [go and get your shoes - use picture, timer/count to signal beginning and end of task etc]

- Reinforcement of desired behaviour [yes/yah shoes. Mummy is pleased because you are helping].

- Clarification of undesired behaviour [if unsuccessful - mummy feels annoyed/angry because we will be late]

Homework:

Implement above plan when/as behaviour 1 occurs.
Continue to monitor behaviour 1 and also record when you used your new plan.
Use before, during after records for behaviour 2.
Continue to monitor all 3 behaviours for frequency.

HANDOUT: Teaching social understanding: the basics...

1. Can your child accurately predict how someone/self will feel given an observable event?

Something nice happens = happy/glad
Something scary happens = scared/frightened
Something accidentally nasty happens = sad
Something deliberately nasty happens = angry/mad

NB: Need to be able to recognise emotions from facial expressions – [sad, mad, glad, scared]

2. Can your child accurately assess/predict how someone/self will feel if they can/can't get what they want/desire?
If you get something you want = happy
If you don't get something you want/get something you don't want = sad

3. Can your child accurately assess/predict how someone/self will feel if they want/don't want something, they think they will/won't get it and they do/don't get it? (Beliefs & Desires)

If you *think* you're getting something you want = happy (even if you don't get it) - then sad
If you *think* you're not getting something you want = sad (even if you do eventually get it) - then happy.

4. Do they understand that 'seeing, feeling, tasting etc (i.e. sensing) leads to 'knowing'?

5. Do they know that a person's beliefs will guide their actions?

6. Do they know that someone else can hold false beliefs and act on them without knowing they were false (even if you did)?

7. Do they understand that someone can hold quite different desires/beliefs/ knowledge from their own desires/beliefs/knowledge and that is OK?

These features are impaired in individuals with an ASD. Do not take them for granted!

SESSION SEVEN

Focusing on Behaviour from an ASD Perspective

Go over homework task per person. Share as a group.

Discuss observations made over past week.
What changes did you implement?
What happened/outcomes?
Discuss any new problems/issues.

Collect record sheets – behaviour 1.

Communication is another part of the ASD picture. Some errant behaviours have been found to decrease in response to strengthening appropriate communicative responses.

NB: Behaviour has been learnt over a period of time and will take time to alter.

Share behaviour 2.

Repeat outline from last week for behaviour 2.
How can we change things to alleviate this behaviour?
Given what you understand of why your child is doing *x* – what would you now do to change the situation?
What is the behaviour telling us about the child's abilities/lack of social understanding?
Where are the deficits and how can we help our child overcome this lack of social understanding?

Teaching new behaviours can be achieved by:-

- Small steps
- Understanding normal development/tasks
- Using naturalistic teaching opportunities
- Systematically reinforcing desired behaviour
- Setting up errorless learning situations
- Helping to introduce the new behaviour in multiple settings to increase skill generalisation.
- Use child's interests, direction to aid motivation for new task
- Teach responsivity to multiple cues e.g., red ball cf. red or ball.
- Use of self-management techniques to facilitate generalisation once skill is mastered so parental assistance can be withdrawn in multiple settings.

Homework: Implement new plan.
Continue to monitor behaviour 1 and 2. Record behaviour 3.

SESSION EIGHT

Focusing on Behaviour from an ASD Perspective

Go over homework task per person. Share as a group.

Discuss observations made over past week.
What changes did you implement?
What happened/outcomes?
Discuss any new problems/issues.

Collect record sheets – behaviour 2.

Share behaviour 3.

Repeat outline from last week for behaviour 3.
How can we change things to alleviate this behaviour?
Given what you understand of why your child is doing *x* – what would you now do to change the situation?

When working with obsessions consider:
Why do you understand your child to engage in obsessive behaviour?
Use obsessions and interest to guide change.
Start obvious, use strict plans/explanations and reduce as the child begins to 'trust' you (or rather gains trust in a more predictable environment).

Homework:
Implement new plan.
Continue to monitor behaviour 1, 2 and 3.

SESSION NINE

Maintenance of New Behaviour/Skills and Self-Management

This is the final session in this programme. You have learnt two different techniques to manage three chosen behaviour's of your child.

1. Functional Applied Behaviour Analysis Approach

In this part of the course, you learnt to view your child's behaviour as a means of communication. You identified the function underlying the behaviour (i.e., what the purpose underlying the behaviour was) and then replaced it with a more socially appropriate behaviour which also fulfilled the same function for the child. Then you made the original disruptive behaviour *non-functional* by removing reinforcement/function of the behaviour.

2. Social Understanding Approach

In this part of the course you learnt that understanding the nature of ASD provides unique techniques/direction when dealing with your child's behaviour. You learnt to view problem behaviours as skills deficits or environmental deficits rather than errant or naughty behaviour. Individuals with an ASD see their world very differently to us and do not have the ability to 'mind-read'. This leads to problems with social understanding which permeates all situations/interactions. You have learnt to use techniques designed to promote social understanding in your interactions with your child.

In each part of the course, you have practically applied the techniques on at least three behaviours and have recorded and monitored preliminary records and outcomes and planned you specific mode of action.

How do these two approaches work together?

It is my opinion that an understanding of ASD allows us to approach our child's behaviours in a pro-active and confident manner. However, when behaviour patterns have formed, a functional applied behaviour analysis approach can be useful to determine the purpose of the behaviour and so guide us to make effective changes. Within this process, an understanding of ASD allows us to also consider what the typical functions of behaviour may be for our particular child. For example, for the child with an ASD, it may be more likely that disruptive behaviour is a response to situations that cause heightened anxiety or a reaction to situations where expected behaviour/social understanding is unclear as opposed to attention-seeking or manipulation.

Moving Forwards...

Own management of future behaviour issues: Aim – to prevent disruptive behaviours becoming established and enhance social understanding/increase child's awareness of effects of behaviour on self/others.

1. Plan/prepare child for *expected desirable behaviour* using visual techniques, simple verbal instructions and social understanding of situation/behaviour – both for you and the child.
2. Answer questions, clarify expectations – use rules and repeat as necessary.
3. Praise desired behaviour often.
4. If disruptive behaviour occurs – gain child's attention immediately. Describe problem and re-state expectations/rules.
5. If child obeys – praise/thank/use social understanding.
6. If problem continues – give instruction to stop.
7. If problem continues – immediately use logical consequences etc.

After issue quietened – use simple verbal/visual explanation to re-state expectations and illustrate what actually occurred/reactions/outcomes etc.

All of the techniques taught in this programme can be applied to other children/siblings and settings following the same procedures. You now have most of the information to effect positive behaviour change with your child/children. However, as the old adage goes – practice makes perfect (or at least positive!). As has been outlined during the course – these approaches are not automatic ways of thinking about child behaviour nor are they common knowledge. This means that you are unlikely to meet others in your social circles who practice the same techniques and therefore you are unlikely to receive external (or social) 'reinforcement- for your approach to child behaviour beyond the benefits you perceive for your own child and family. The continued use of these techniques can therefore become difficult. However, we can ease this task somewhat by enlisting the help of others – explaining the techniques to partners/older children – and by passing some of the responsibility for maintenance of new behaviours on to the child themselves.

To date, you have been monitoring your child's behaviour, devising plans and evaluating the effect of the said plan of action. Your child can be enlisted to help with some of these tasks and they are in fact usually very good at monitoring their own behaviour. The ability to 'manage' one's own behaviour is a positive progression and has numerous advantages for the child e.g., promotes self-awareness, awareness of own behaviour and effects of behaviour, promotes new learning of consequences and behaviour and steps required to negotiate behaviour to acceptable conclusions, places management of behaviour with child rather than being imposed by others outside the situation/understanding and encourages the child to take responsibility for own behaviour.

How?

The following principles apply and can be adapted to meet your own/your family and child needs:

Set up *self-monitoring system* and focus on expected/positive behaviours e.g., use charts/visual schedules and let them mark off desirable behaviours. Once trained, leave the child to fill in own records – occasional monitoring/checking will soon be able to give way to the child taking complete responsibility.

Consider behaviour 1;

How could you include your child in the monitoring of this behaviour?

Repeat for behaviour 2:

Behaviour 3:

In conjunction, include your child in determining the outcomes for both desirable behaviour achieved and undesirable behaviour occurrences.

Set up positive learning situation;

1. Set some sort of *goal* that your *child* would like to work towards i.e., how many times should this behaviour occur to reach goal (behaviour is no longer a problem)?
2. Give frequent *praise/reinforcement* for efforts (both at keeping records by self and for outcomes).
3. Perhaps also let child *decide own limits* e.g., if *x* number of positive behaviours – go swimming this weekend or bake a cake. Make this an expected activity that fits in with the family as much as possible rather than a specially contrived reward which takes more effort and planning. The advantage with this approach is that the child quickly learns the consequences for his/her own actions and contrary to expectations – they seldom fiddle the system! This is one of those situations where our child's inability/difficulty with lying may come in handy.

Simple wrist counters (from sports shops) have been found to be useful for those children who like details and can be taught to record numbers of times they performed a desirable behaviour (good for maths too).

For the older child – *include them in planning* in an many situations as possible. Sit down and plan with your child before new situations and let them provide solutions for handling potential problems. Use 'what if…' or 'what should we do when…' and let them conclude. Draw their attention to their own plan. This is a good method for drawing their attention to the situation at hand rather than being caught up in something they believe they have no control over/understanding of.

The training of self-management involves getting the child to

1. Select and set a goal
2. Monitor own progress and/or
3. Plan/arrange own environment
4. Evaluate own progress

In other words – include your child in their own behavioural management.

This step takes more work initially but within a short period, your child should be able to accurately assess and monitor their own behaviour/s.

Thus endeth the course!

NB: two further follow-up record sessions will be organised for 2001. Records will be similar to those already viewed/filled out. You will be asked to keep one week's records of the behaviours 1-3 currently of interest. These forms will be posted to you with instructions closer to the time. Expected dates are late January and May/June.

Thank you!

HANDOUT: Increasing & Decreasing Behaviour:

Increase behaviour:

- Attend to child, get involved and observe closely.
- Catch them at positive behaviour, be vigilant.
- Initially attend often and immediately.
- Comment/use visual pictures to convey enthusiasm and encouragement about the use of desirable behaviour including social and play situations.
- Offer help if useful.
- Use positive non-verbal behaviour.
- Use 'I' statements.
- Vary your positive responses.
- Respond to child requests, questions, comments.
- Keep interactions short – 30-60 sec.
- Set interesting scene.
- Model and comment on what you are doing.
- Repeat, clarify, check understanding.
- Prompt as necessary.

Decrease undesirable behaviour:

- Plan.
- Communicate plan/rules – write or use visual methods to accompany words spoken.
- Get child's attention.
- State problem behaviour – simple, brief, calm.
- State desired behaviour (include short social understanding statement i.e., - why you want them to do this behaviour).
- Rehearse desirable behaviour.
- Outline consequences.
- Allow time for compliance.
- Follow continued non-compliance immediately with stated consequence.
- Be consistent and immediate.
- Use positive feedback of changed/desirable response.
- After correction process – repeat rule and try to catch desirable behaviour and reinforce.
- Give example of positive behaviour.
- Don't debate/argue.
- Ignore response to correction procedure.

Appendix D

Record Form

Name:

Key Behaviours of interest:

☐

☐

☐

	Mon	**Tues**	**Wed**	**Thurs**	**Fri**	**Sat**	**Sun**
7am							
7.30							
8.00							
8.30							
9.00							
9.30							
10.00							
10.30							
11.00							
11.30							
12.00							
12.30							
1 pm							
1.30							
2.00							
2.30							
3.00							
3.30							
4.00							
4.30							
5.00							
5.30							
6.00							
6.30							
7.00							
7.30							
8.00							

Appendix E

Beliefs and Attributions

Think about a recent problem behaviour that your child engaged in....

Describe briefly:

What is your first and main explanation for why ---------- is behaving like this?

1. How likely is it that ---------- will behave like this again?

Extremely Unlikely	Very Unlikely	A Little Unlikely	Neither Unlikely or Likely	A Little Likely	Very Likely	Extremely Likely
1	2	3	4	5	6	7

2. How likely is it that this is a one-off unusual behaviour?

Extremely Unlikely	Very Unlikely	A Little Unlikely	Neither Unlikely or Likely	A Little Likely	Very Likely	Extremely Likely
1	2	3	4	5	6	7

3. How likely is it that others will engage in this behaviour?

Extremely Unlikely	Very Unlikely	A Little Unlikely	Neither Unlikely or Likely	A Little Likely	Very Likely	Extremely Likely
1	2	3	4	5	6	7

4. How likely is it that this behaviour is specific to ----------?

Extremely Unlikely	Very Unlikely	A Little Unlikely	Neither Unlikely or Likely	A Little Likely	Very Likely	Extremely Likely
1	2	3	4	5	6	7

5. How likely was the behaviour was caused by some characteristic of --------(e.g., psychological, physical or behavioural characteristic)?

Extremely Unlikely	Very Unlikely	A Little Unlikely	Neither Unlikely or Likely	A Little Likely	Very Likely	Extremely Likely
1	2	3	4	5	6	7

6. How likely were influences of the situation (e.g., other people, setting, environment) responsible for the behaviour?

Extremely Unlikely	Very Unlikely	A Little Unlikely	Neither Unlikely or Likely	A Little Likely	Very Likely	Extremely Likely
1	2	3	4	5	6	7

7. How likely is it that --------- could have controlled their behaviour and changed the outcome?

Extremely Unlikely	Very Unlikely	A Little Unlikely	Neither Unlikely or Likely	A Little Likely	Very Likely	Extremely Likely
1	2	3	4	5	6	7

8. How likely is it that the outcome was inevitable and couldn't be changed?

Extremely Unlikely	Very Unlikely	A Little Unlikely	Neither Unlikely or Likely	A Little Likely	Very Likely	Extremely Likely
1	2	3	4	5	6	7

Appendix F

Interview Schedule

Child's Name:
Date Of Birth:

Family Details:
Family Structure (who else is in the immediate family)

Extended family:

Major support people/alternative caregivers:

Relationship with significant others (siblings, partner, etc):

Key qualities of support people:

Culture/ethnicity:

Predominant beliefs/practises:

Relevant Medical History
Diagnostic History:

When made:

By Whom:

Professionals involved in child's care:

Family Interests
Family interests

Child interests

Involvement outside home

Typical week/weekend:

	Activities
Monday	
Tuesday	
Wednesday	
Thursday	
Friday	
Saturday	
Sunday	

Stressors – (financial, time out, relationship with child)
What are the stressors that interfere with you doing your best as a parent?

1.

2.

3.

4.

5.

Rank your relationship with your child generally:

Poor/non-existent Not so good Fair Good Excellent

Behavioural/skill Issues
Nature of challenging behaviours/new behaviours sought:
1.
2.
3.

Additional:

Attributions of child's behaviours:

Previous management history:

Current parenting strategies:

Goal behaviours/skills:

Parenting History:
How did your parents raise you?

How do you feel about going to a professional to help you deal with your child?

What child behaviours are most appreciated by you as parents?

What parenting behaviours work best in changing your child's behaviours?

Which ones work least well?

What would make it more likely that you are able to attend all the sessions in this parenting programme?

What are your future hopes/goals for your child?

What are your fears for your child?

Appendix G

Evaluation Form

You have now completed the nine week course aimed at increasing understanding of your child's behaviours associated with Autism Spectrum Disorder.

Please fill in the following evaluation form. Feel free to note any comments at any stage. As outlined in the participant information data before this course commenced, it is intended that this program (or a revised version) be made available to other parents and perhaps education providers. It is therefore useful for me and important to others that you feel able to evaluate the program honestly and freely. Thank you.

Functional Applied Behaviour Analysis Approach

1. *How useful did you find this section?*

Not Useful At all		Half Useful		Extremely Useful
1	2	3	4	5

Comments:

2. *How did you find the presented material*?

Not clear/ Very confusing		OK		Very clear/ Easy
1	2	3	4	5

Comments:

3. *How confident did you feel about this approach to behaviour before this program*?

Not confident		50%		Very Confident
1	2	3	4	5

Comments:

4. *How confident do you feel about this approach to behaviour now*?

Not confident		50%		Very Confident
1	2	3	4	5

Comments:

5. *How likely is it that you will use this approach to your child's behaviour/s again?*

Not Likely		Maybe		Very Likely
1	2	3	4	5

Comments:

6. *Other comments/suggestions about this applied behaviour analysis approach to behaviour*?

Autism Specific Disorder/ Social Understanding Approach

7. *How useful did you find this section*?

Not Useful At all		Half Useful		Extremely Useful
1	2	3	4	5

Comments:

8. *How did you find the presented material?*

Not clear Very confusing		OK		Very clear Easy
1	2	3	4	5

Comments:

9. *How confident did you feel about this approach to behaviour before this program*?

Not confident		50%		Very Confident
1	2	3	4	5

Comments:

10. *How confident do you feel about this approach to behaviour now?*

Not confident		50%		Very Confident
1	2	3	4	5

Comments:

11. *How likely is it that you will use this approach to your child's behaviour/s again?*

Not Likely		Maybe		Very Likely
1	2	3	4	5

Comments:

12. *Other comments/suggestions about this ASD specific approach to behaviour?*
You have experienced some degree of behaviour change during this course.

13. *Overall, how do you rate the behaviour changes noted for;*
Behaviour 1?

Very Negative		No Change		Very Positive
1	2	3	4	5

Behaviour 2?

Very Negative		No Change		Very Positive
1	2	3	4	5

Behaviour 3?

Very Negative		No Change		Very Positive
1	2	3	4	5

14. *How much change did you attribute to techniques learned during this program*?

None		50%		All
1	2	3	4	5

15. *What else did you attribute behaviour change to*?

16. *Did you find one approach (i.e. ASD versus Applied behaviour Analysis) more useful than the other?*

Yes/No

If Yes, which one?

Comments:

Please comment on being part of a group program -
17. *Did you find the group*

Positive/Negative

Comments:

18. *What are your thoughts on the length of the program?*

19. *Please make any other comments/suggestions about the program:*